Leicester, Leicestershire and Rutland LeDeR Annual Report 2024

Leicester, Leicestershire and Rutland
Health and Wellbeing Partnership

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Foreword

The ongoing commitment from Leicester, Leicestershire and Rutland (LLR) to the LeDeR programme and improving the care of people with a learning disability (LD) and autistic people is what enables the annual LeDeR report to be produced. Thank you for the ongoing dedication, commitment and passion of many people and organisations across the LLR system who have notified deaths of people with a LD and autistic people, conducted reviews, and coded and analysed the information. Most importantly though, we wish to acknowledge the people for whom this report is created: people with a LD and autistic people, their families, their friends, their colleagues, carers, and all staff and service providers whose lives are affected by this report. Lastly, our LeDeR Reviewers, as without their expertise, experience and passion we would not be where we are today. Whilst many people can no longer be with us today, we hope that this report honours their lives.

We must not rest upon the contents of this report. Instead, all partners across the LLR health and social care sector must embrace the findings of this report; everyone has a role to play. Only then will we ensure that every person with a LD and autistic people receive the high quality of care that they deserve. Only then will we achieve health equality and equity.

Caroline Trevithick, Chief Nurse & Executive Director, Leicester, Leicestershire and Rutland Integrated Care Board

Santokh Dulai, Assistant Director (Adults & Communities), Leicestershire County Council

David Williams, Group Director of Strategy and Business Development, Leicestershire Partnership NHS Trust and Northamptonshire Healthcare NHS Foundation Trust

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NHS England National Team (NHSE)

NHS England Regional Team

LLR LeDeR Team

LLR LeDeR Experts by Experience

LPT Talk and Listen Group

All family members' contributions

Leicestershire Partnership NHS Trust

University Hospitals of Leicester NHS Trust

Primary Care Services

Leicester City Council

Leicestershire County Council

Rutland County Council

Leicester, Leicestershire and Rutland Child Death Overview Panel (CDOP)

Leicester, Leicestershire and Rutland Integrated Care Board

DeMontfort University

Executive Summary

The 2024 LeDeR (Learning from Lives and Deaths of People with a Learning Disability and Autistic People) annual report for LLR takes us through changes to the LeDeR process since last year and describes further changes for the year ahead.

The 'Reviews of Deaths' section explains how data is presented and breaks down the data by demographics for comparison, revealing causes of death by demographic group, and further examining the leading causes of death in LLR.

Quality of care is measured by ten key themes set out nationally and further examined by sub-theme.

Preventative healthcare has featured heavily in 2022/23 and LLR LeDeR has been actively involved in supporting working groups to which the programme contributes learning into action and highlights in this report for 2023/24.

Thematic analysis carried out throughout the year is described, and has also been shared with national teams, notably the authors of the new 'Right Care' report.

CDOP cases and changes to policy are explained, followed by some achievements and LeDeR contributions made in the local system.

Learning into action detail is followed by the LLR LeDeR top ten points, which is also highlighted below for ease of access. Plans for the forthcoming year can be found later, with appendices containing more detail in relation to various sections of the report.

In all, it has been a very challenging and positive year for LLR LeDeR.

Throughout the report, there are direct quotes from friends and family, shown in coloured bands across the pages.

"The home had staff working there who could speak Gujarati, who were able to speak and sing to him in Gujarati. This is something he appeared to enjoy, even if he couldn't respond to them."

Top Ten Learning into Action Points

1. Report the deaths of those people autism (with or without a LD) to the LeDeR Programme.

2. Report the deaths of those from Leicester City and from diverse ethnic backgrounds to the LeDeR Programme.

   LeDeR population analysis in 22/23 revealed that we are receiving notifications to LLR LeDeR as expected from Leicestershire County and Rutland of deaths of those from a diverse ethnic background. However, notifications from Leicester city specifically were and continue to be much lower than expected of the deaths of those from a diverse ethnic background.

3. The system continues to be unsuccessful in the correct application of the Mental Capacity Act (MCA) (2005), in practise, for people with a LD and autistic people. Many professionals have legal obligations under the MCA, but they are not being fulfilled at a system level.

4. The practice of estimating someone's weight is a significant risk for people. People should know where to access suitable weighing equipment locally.

5. Clear plans should be created for every person with behaviour that challenges, highlighting the support they require and anticipating the support they are likely to need in the years ahead. This should be reflected in future commissioning considerations in LLR for provision of residential care for those with a LD, as physical health and nursing care needs increase particularly towards the end of their life.

6. Care providers must be competent and confident in talking about end-of-life matters and having these meaningful conversations at the right time. It is important to instigate Advanced Care Plans early enough.

7. Screening inequalities exist, and every effort should be made to improve the uptake. Barriers to non-invasive bowel screening should be rectified. Full implementation of the Reasonable Adjustment Digital Flag is recommended.

8. Better understanding of the STOMP/STAMP agenda across generic, physical, and mental health services.

9. Aspiration pneumonia happens as a consequence of a precipitating event. Identification of risk factors and ongoing management are key. This requires a multi-disciplinary approach.

10. There remains barriers to successful venepuncture for people with a learning disability, system challenges in limited availability and understanding of what can be done. This is especially for people who require a high level of reasonable adjustments to achieve successful blood test.

Introduction

The LeDeR programme continues to complete initial or focused reviews for people. Where possible we have drawn comparisons over time but have also highlighted where, due to the transition in the system of data collection, this was not possible. The LeDeR programme has for the second year running, included LeDeR reviews of autistic people. As this is the second year, it was hoped there would be some data to draw upon, however the notifications of deaths of autistic people remain extremely low and therefore, it is important to maintain confidentiality. Notifying a death to LeDeR is not mandatory and, therefore we would not expect LeDeR to have data on all people with a LD and autistic people who have died in LLR. Some data contains relatively small numbers of cases, so some findings must be interpreted with a degree of caution.

National context[1]

Learning from Lives and Deaths - people with a LD and autistic people (LeDeR), previously known as The English Learning Disabilities Mortality Review (LeDeR) programme, was established as a pilot in 2015 and rolled out nationally in 2017. The aims are to:

1. Improve care for people with a LD and autistic people.
2. Reduce health inequalities for people with a LD and autistic people and
3. Prevent people with a LD and autistic people dying prematurely.

Since being established, deaths of people with a LD, and from January 2022 autistic people, have been reviewed with the findings presented in the LeDeR annual reports, where the action from learning has been captured.

"He was born during the Second World War - Steam engines were his biggest passion he would go on days out to the Great Central Railway. He celebrated his 70th birthday on the Loughborough to Leicester line Sunday lunch included."

[1] *National LeDeR Report 2021*

Glossary of abbreviations

AAA	-	Abdominal Aortic Aneurysm
ACP	-	Advanced Care Plan
AHC	-	Annual Health Check
ALN	–	Acute Liaison Nurse
ASC	–	Adult Social Care
BMI	-	Body Mass Index
CDOP	–	Child Death Overview Panel
CNLD	-	Community Nurse Learning Disabilities
CPR	-	Cardio Pulmonary Resuscitation
CRIST	-	Crisis Response Intensive Support Team
CT Scan	-	Computed Tomography Scan
DISDAT	-	Disability Distress Assessment Tool
DNA	-	Did Not Attend
DNACPR	–	Do Not Attempt Cardio-Pulmonary Resuscitation
EBE	–	Expert by Experience
EoL	-	End of Life
GP	–	General Practitioner
Hb	-	Hemoglobin
ICS	–	Integrated Care System
IMCA	–	Independent Mental Capacity Advocate
LeDeR	–	Learning from Lives and Deaths Review Programme
LD	–	Learning Disability
LLR	-	Leicester, Leicestershire and Rutland
MCA	–	Mental Capacity Act
MDT	–	Multi Disciplinary Team
NHS	–	National Health Service
NICE	–	National Institute for Health and Care Excellence
NOK	-	Next of Kin
PBS	–	Positive Behaviour Support
PEG	–	Percutaneous Endoscopic Gastrostomy
PCLN	–	Primary Care Liaison Nurse
ReSPECT	–	Recommended Summary Plan for Emergency Care and Treatment
SALT	-	Speech and Language Therapist
SHAW	-	Safe, Healthy and Well
SMART	–	Specific Measurable Actionable Realistic Timebound
STAMP	–	Supporting Treatment and Appropriate Medication Treatment in Paediatrics
STOMP	–	Stopping the Over Medication of People with LD and Autistic People
UHL	-	University Hospitals Leicester

Reviews of deaths

Deaths notified to the LLR LeDeR programme.

A total of 94 deaths of people with a LD and autistic people were notified to the LLR LeDeR Programme from 1st April 2023 – 31st March 2024. Of those people:

- 1 person was autistic.
- 22 were out of scope (1 CDOP and 21 adults without LD or autism diagnosis).
- 11 were adults with a LD and autism.
- 60 were adults with a LD.

Referrals received in year.

Figure *1* below shows a total of 94 deaths referred to LLR LeDeR in 2023/24, broken down into initial and focused categories. At end of year, 23 cases remained in progress and 48 had been completed.

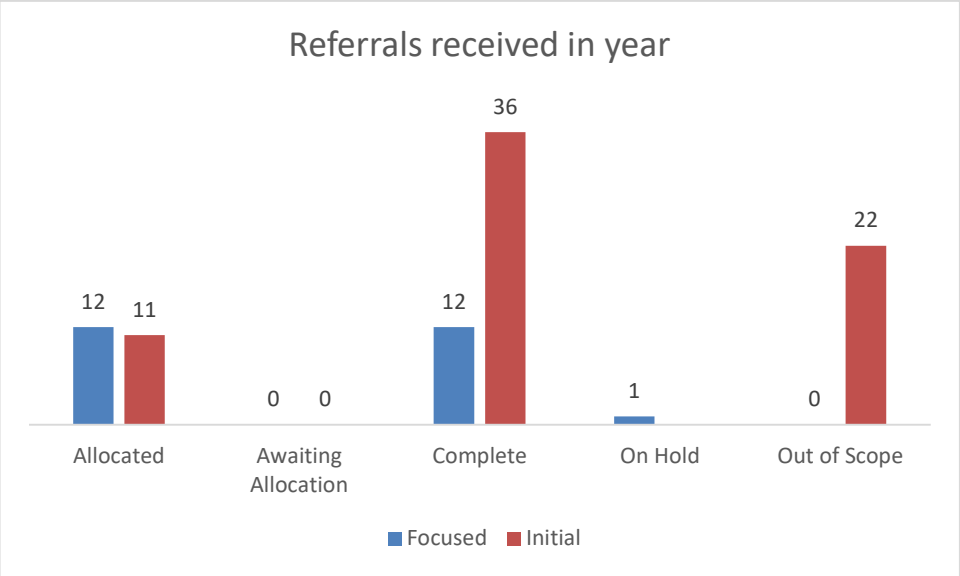


Figure 1. Referrals received by type, 2023/24

Age at death in 2023/24

Median age at death for those who passed away and their deaths notified to LeDeR in 2023/24, the median age at death was 66yrs. This has increased since last year which was 62yrs.

Please note, that the deaths of children are no longer included.

The median age of death was 65yrs for those from a Diverse Ethnic background and 66yrs for those from a White British background.

The median age at death in 2023/24, was 66yrs.

Mean age at death. As the annual report has been commenced since 2021, it felt an appropriate time to statistically consider previous years with regards to the mean age at death. To ensure this was comparable two sets of data are shown, the first includes the deaths of children (CDOP) and the second excludes CDOP. This is because CDOP was taken out of the LeDeR programme in 2023.

Mean Age of Notifications received by LLR in Financial year including CDOP	
2021/2022	56 years
2022/2023	58 years
2023/2024	59 years

Mean Age of Notifications received by LLR in Financial year excluding CDOP	
2021/2022	59 years
2022/2023	62 years
2023/2024	59 years

The mean age at death in 2023/24, was 59yrs.

Month of death

The 72 deaths referred to LeDeR and eligible for a LeDeR review in this time-period as shown in *Figure 2. Month of death*, with more deaths occurring in April than any other month. This excludes 6 notifications received in 2023/24, who died prior to this reporting year. This is broken down in *Figure 3. Month of death by gender.* It is expected in the United Kingdom (UK) to see seasonal differences as sadly more deaths generally occur during the winter period.

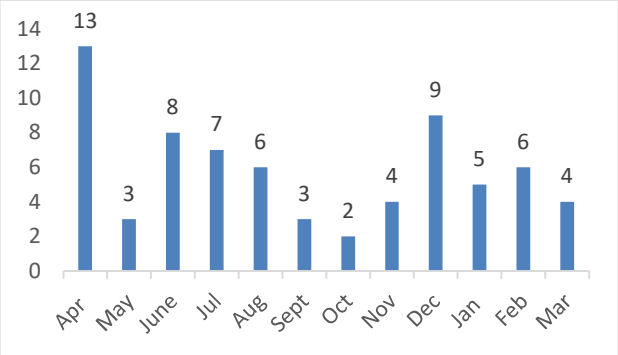


Figure 2. Month of death

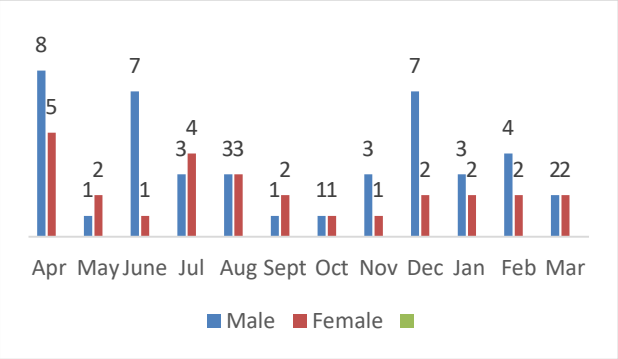


Figure 3. Month of death by gender

Reviews completed in year.

Analysis from this point covers all reviews that were completed within the 12 months from April 2023 to March 2024, rather than those received in that period.

This enables comparison with previous reports, and it is possible only to report accurately on cases that were completed at the time of writing.

In 2023/24, the LLR LeDeR programme completed 82 reviews, 51 of which were initial, 31 focused, *Figure 4. Reviews completed in 2023/24*. The key performance indicator set nationally is that 35% of LeDeR Reviews are to be focused.

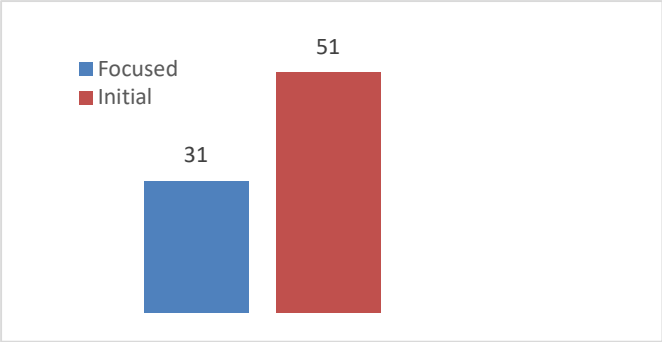


Figure 4. Reviews completed in 2023/24

For LLR LeDeR 37% of reviews were focused during 2023/24.

An initial review is a comprehensive review looking at key episode of care.

A focused review includes the initial review as well as detailed learning into action and is presented at the LLR governance panel.

Equality Impact & Demographic Data

Age Group

Deaths were broken down by age group, *Figure 5. LLR LeDeR Deaths by age group 2023/24*, 51% of people with a LD who died were aged 61yrs or older, which is an increase since the past year, and 49% of people were 60yrs or younger. By comparison, deaths by age group in 2022/23 in LLR LeDeR, *Figure 5a Deaths by age group 2022/23* shows 44% of people were aged 61yrs or older and 56% were 60yrs or younger. For wider comparison, an average age at death for people with a LD is 60-65yrs and for the general population this is 85-89yrs.

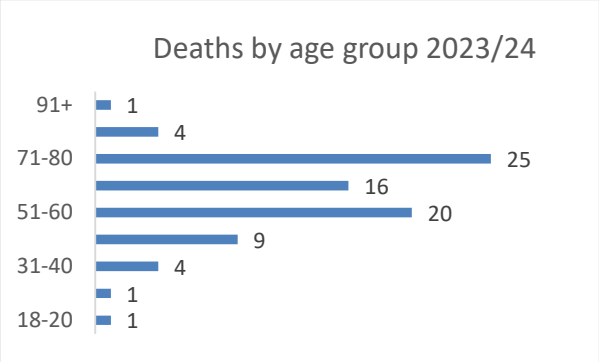


Figure 5. LLR LeDeR Deaths by age group 2023/24

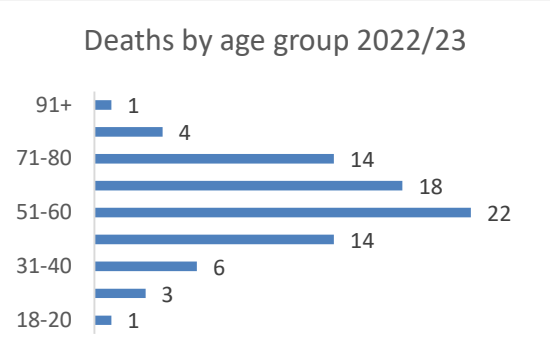


Figure 5a. LLR LeDeR Deaths by age group 2022/23

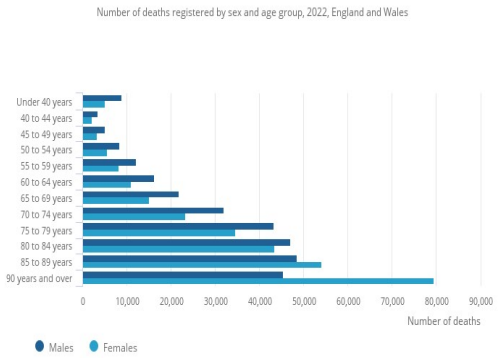


Figure 6. Death registration summary by age ONS

Median age at death in completed reviews.

The median age of deaths in completed reviews in 2023/24 is 65yrs.

It is important to note that from July 2023, child deaths were no longer referred to LeDeR and so LeDeR are reporting only on deaths of people aged over 18yrs.

"She always loved the 2p slot machines at Mablethorpe! She absolutely hated the sea but she loved the beach, well, when the tide went out! She would sit and play or paddle in shallow pools or puddles."

Ethnicity

The deaths of people with a LD and autistic people in LLR were of the following ethnicities, 'White' 78%, with 'Asian or Asian British' comprising 15% and 'Black, African, Caribbean or Black British' 1%, 'Mixed or multiple Ethnic Groups' 1%, 'White and Black Caribbean' 1%. The remaining 4% had preferred not to state. .

Figure 7. Cases completed 2023/24 by Ethnic Group.

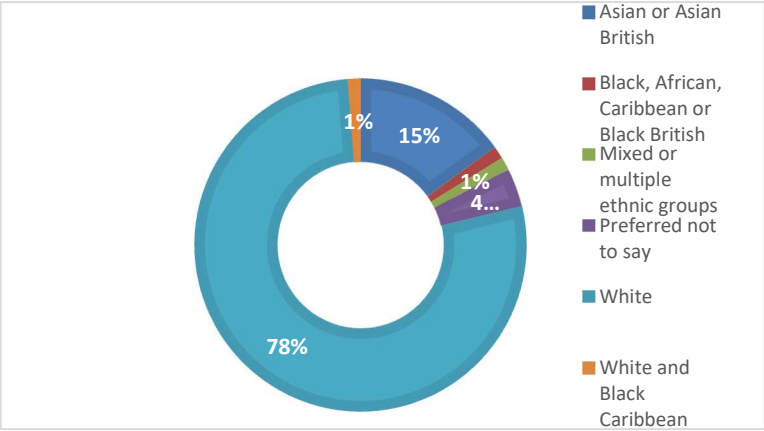


Figure 7. Cases completed 2023/24 by Ethnic Group

Breaking this down further and omitting the 'White' ethnic group allows us to see a clearer picture within different ethnicities, as shown in

Figure 8. Cases completed 2023/24 by

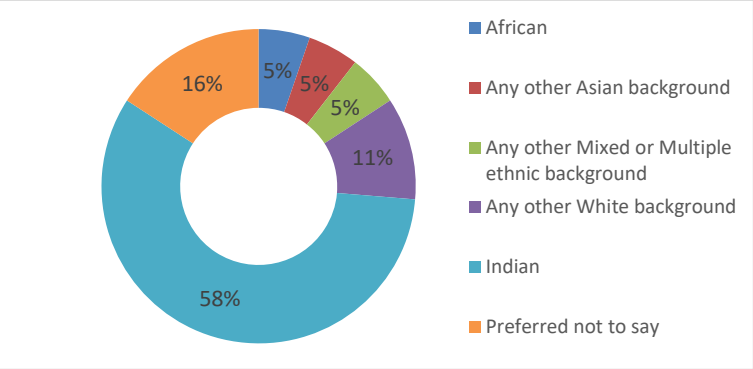


Figure 8. Cases completed 2023/24 by Ethnicity.

As shown in *Figure 9. Deaths by Gender*, 57% of reviews completed in 2023/24 were of males, and 43% of females, which is in line with national and local gender demographics. Those people were resident across all three ICS places, almost evenly for East Leicestershire and Rutland and West Leicestershire but higher in Leicester City as illustrated in *Figure 10. Deaths by ICS Place.*

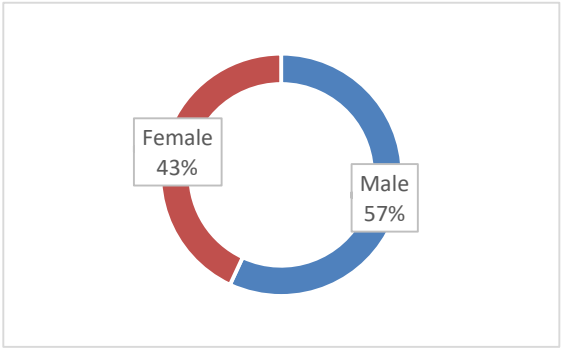


Figure 9. Deaths by Gender

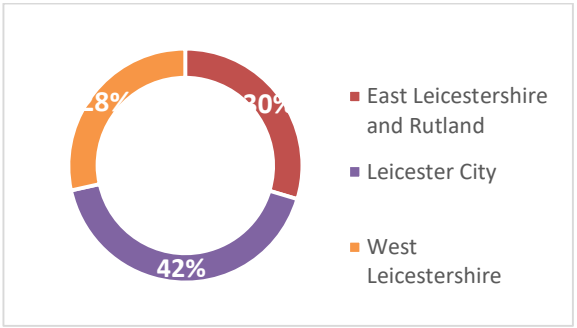


Figure 10. Deaths by ICS Place

Reason for focused review

There are no focused reviews due to being open to the criminal justice system as an offender in the 5yrs previous. Most focused reviews are carried out due to diverse ethnicity. There was one focused review due to the person being under the mental health act under section in the 5yrs previous.

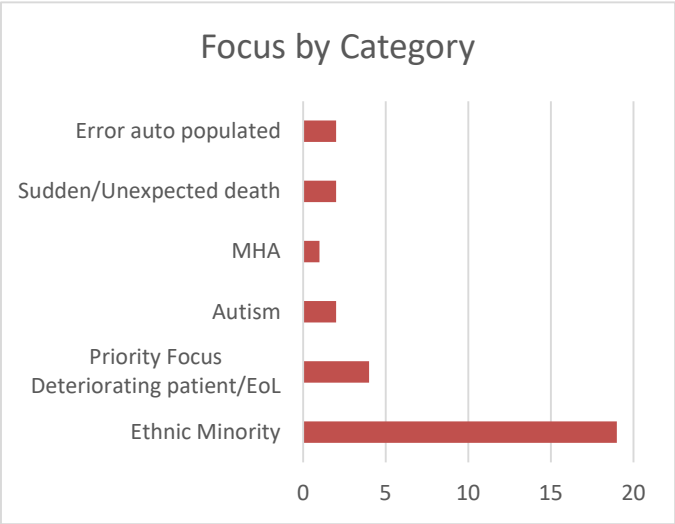


Figure 21.Focus by Category

Intersectionality

Intersectionality continues to be promoted in the LeDeR governance panels and reviews. LeDeR is striving to increase in the learning into action in this area and ensure that governance panels are diverse.

Important Statements from LeDeR

Although a lot of positive, encouraging and at times courageous work and breakthroughs have been seen in the past year for the LLR LeDeR Programme and LLR Health and Social Care System, there are two areas that require immediate action to resolve. Being mindful, that reasonable adjustment by mainstream services of all types is not optional it is a requirement under the Equality Act (2010).

1. The system in LLR continues to be unsuccessful in the correct application of the Mental Capacity Act (MCA) (2005), in practise, for people with a LD and autistic people. This is problematic on impending investigations and treatment creating unnecessary delays and consequently unlawful restrictive interventions. Many professionals have legal obligations under the MCA, but they are not being fulfilled at a system level. This leaves people with a LD and autistic people at increased risk of poorer health outcomes and does not uphold their rights under the MCA. LLR LeDeR urges our local systems to take action that will improve the application of the MCA.

2. People with a LD are at increased risk of communication of pain being misinterpreted or missed altogether, and it is essential to safeguard against this. There are communication tools/passports and a DISDAT (Disability distress assessment tool) that are readily available for people with a LD. Care providers, particularly those who are either not specialist in the field of LD or who do not know the person well, and other services involved in their care must ensure that the communication needs and most importantly how pain is communicated by the person are known, recorded, prioritised and shared. A priority must be with regard to those individuals who are moved away from their care setting into nursing care providers due to end

of life care needs. This information must be shared through clinical records, communication passports and the Reasonable Adjustment Digital Flag.

LLR LeDeR's statement from 2022-23

There is no doubt that some people with a LD receive inconsistent care regarding some of the basic healthcare observations. LLR LeDeR has seen the cases of a number of people who died as a consequence of malnutrition, all of whom were not weighed when they should have been. LLR LeDeR urges the seriousness of rectifying this failure.

There has been an enormous amount of system work in this area which will be highlighted later. Whilst there is still evidence of some inconsistencies with weight management and observations for people with a LD the infrastructure to support and improve this is undeniable. The potential of these new arrangements must now be fully realised by all partners.

Causes and Circumstances of Death

In this section, we summarise the circumstances and most common causes of death of people with a LD and autistic people.

Cause of death by demographic group

Age Group

It is clearly shown in

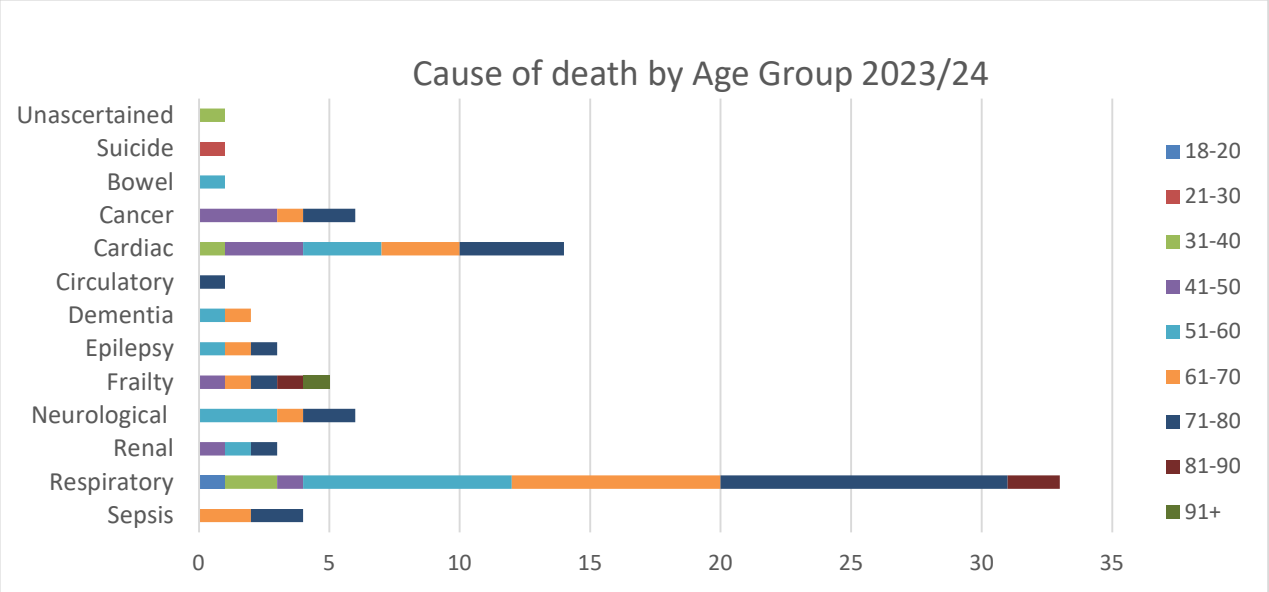


Figure 12. Cause of Death by *Age that the most frequent Cause of Death (CoD) was respiratory illness and that this affected most age groups, notably prominent in people aged between 41 and 70.*

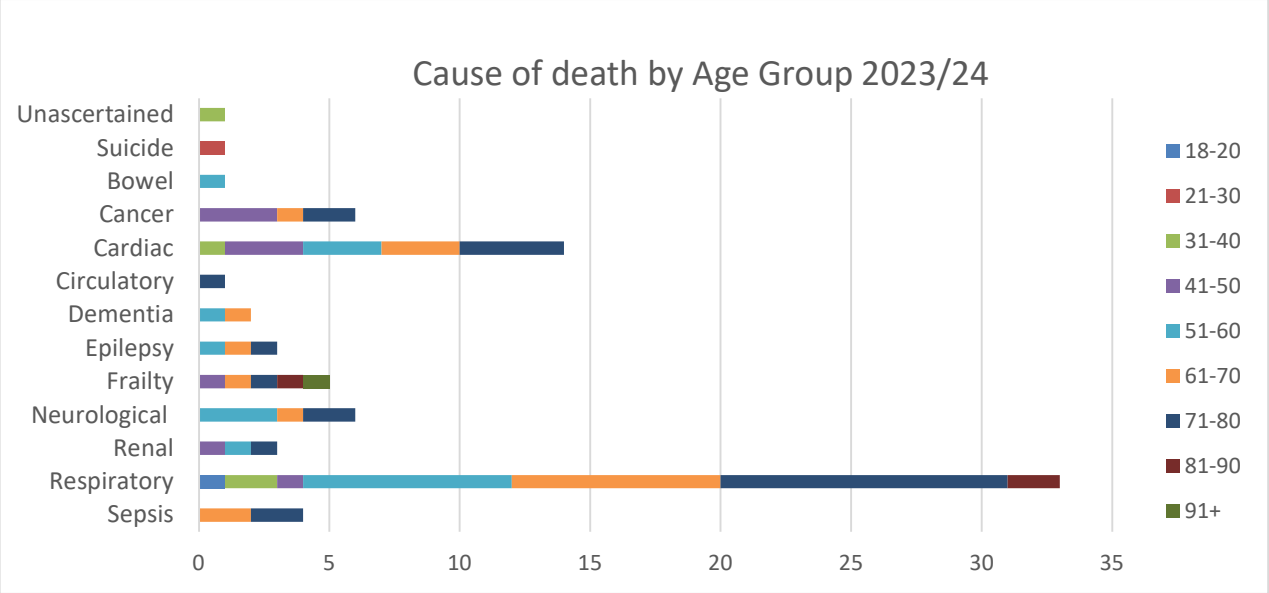


Figure 12. Cause of Death by Age

Breaking down of CoD by Ethnicity is also shown in *Figure 13. Cause of Death by Ethnicity*

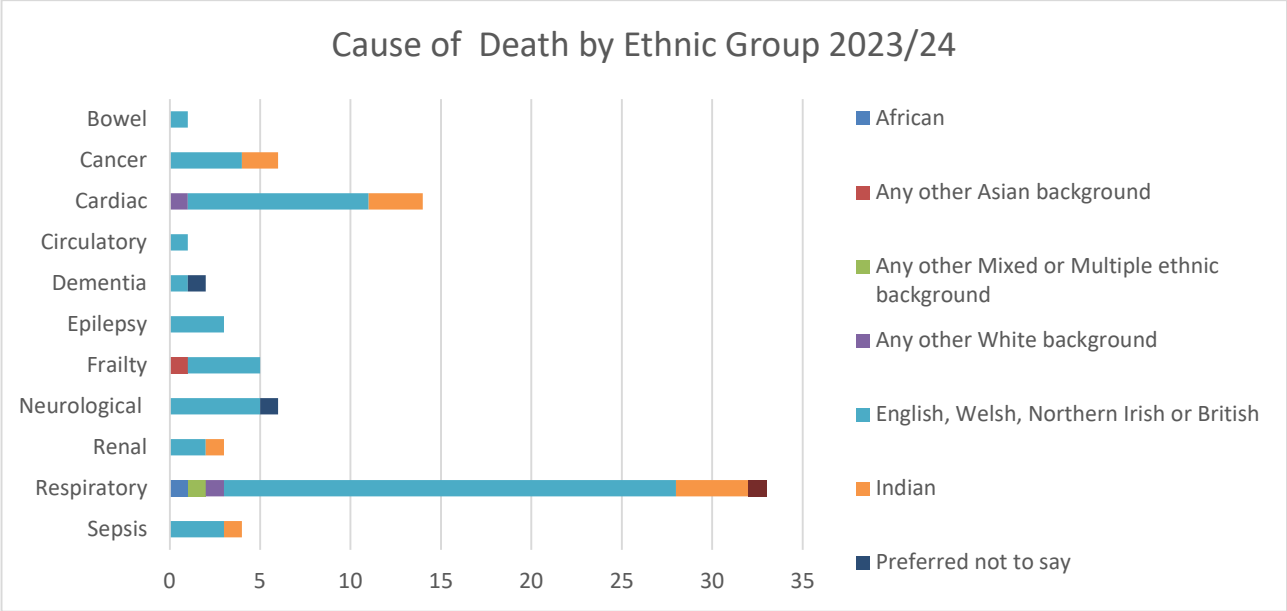


Figure 13. Cause of Death by Ethnicity

Leading Causes of Death

Causes of death in reviews competed in 2023/24 are laid out effectively in Figure 14. Causes of Death, shown below. Respiratory remains the leading cause of death, followed by Cardiac and Cancer

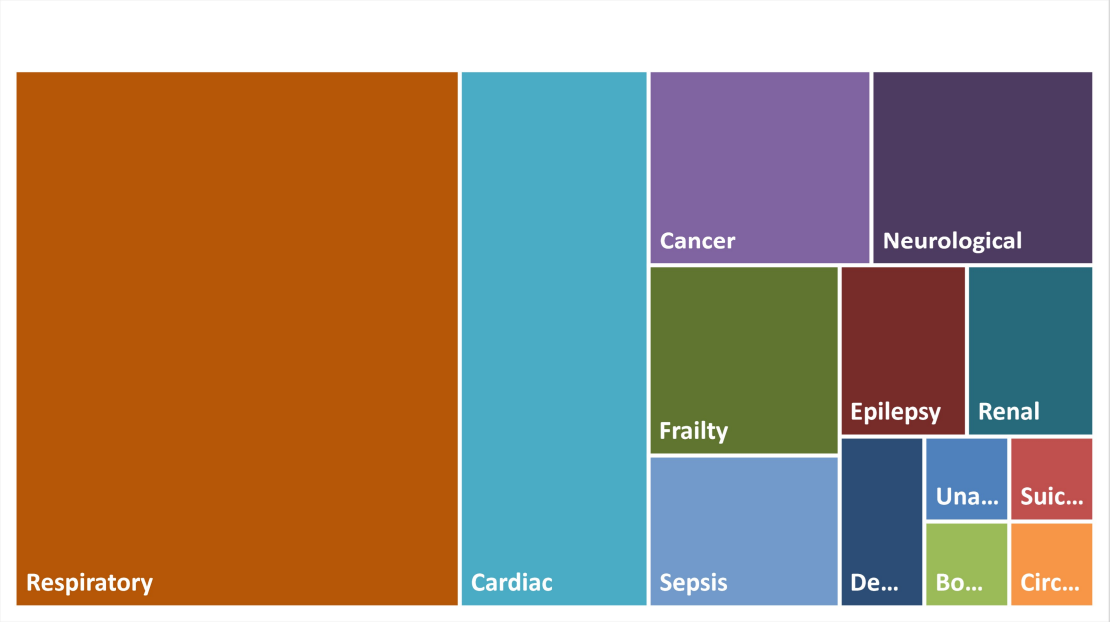


Figure 14. Causes of Death

Respiratory Deaths

Deaths from respiratory causes remains the leading cause of death for those in LLR reported to LeDeR, this figure has reduced slightly since last year. The respiratory thematic analysis can be found in the LeDeR 2021 – 2022 annual report. The aspiration pneumonia thematic analysis can be found in the LeDeR 2022 – 2023 report. Respiratory deaths remain an area of focus for LLR LeDeR particularly with regards to deaths where there were avoidable factors highlighted. The SMART actions continue to progress as learning into action with a dedicated workstream.

What do we want to achieve?

Aspiration pneumonia

We aim to reduce preventable aspiration pneumonia deaths in people with LDs in LLR by adjusting already existing care pathways to include multi-agency response and address the precipitating factors linked to increased risks to aspiration pneumonia.

A comprehensive plan has been agreed based on the findings and will be implemented with the support of the LDA Collaborative partners during 2024-25. These recommendations are ambitious and require a whole system approach. The aspiration pneumonia analysis is currently being written up as a journal article to enable ongoing learning and research in this area. An aspiration pneumonia protection plan and risk assessment are being created and is currently in an initial draft stage. NHS England produced the 'Right Care Scenario' which is an excellent resource and can be found here:

20241402-Learning-disability-and-aspiration-pneumonia-FINAL.pdf (gettingitrightfirsttime.co.uk)

Cardiac

Deaths from cardiac causes has increased since last year and remains the 2nd leading cause of death for people with a LD in LLR. Most people were overweight, obese or had morbid obesity recorded for their BMI category, which is known to increase the risk of heart and circulatory diseases. It would be beneficial to increase awareness for people with a LD of healthy hearts and what measures can be taken to optimise cardiac health. LPT have employed a strategic dietician for LD, the focus is on health promotion, active lifestyle and healthy weight management and should be widely supported. The types of cardiac issues included: ischaemic heart disease, hypertensive heart disease, coronary atherosclerosis, and biventricular hypertrophy.

Cancer

LLR LeDeR has seen a rise in the deaths from cancer this year, now reaching the 3rd leading cause of death for people with a LD. This could be due to improved cancer diagnosis for people with a LD and more people receiving diagnostic tests than has been seen previously. However, the area of concern is the number of people who received a late cancer diagnosis, which was 4 out of the 6 people. Areas of concern included issues around the use of the Mental Capacity Act (2005), lack of comprehensive clinical assessment and referral follow up, particularly oncology follow up. It is

clear to see that much work is to be done with earlier cancer diagnosis in people with a LD, it is recommended that health and social care professionals work together to ensure equality of outcome for cancer care for this population. Improvements should be prioritised in cancer screening and access to routine primary healthcare testing such as blood tests. The types of cancer included; mouth, oesophageal, breast, gynaecological and bowel.

"He was always happy and smiling and his Grandma called him her little ray of sunshine".

Quality of Care

High quality health and social care is of paramount importance for people with a LD and autistic people. However, evidence has demonstrated that this is sometimes not the case and sadly, the impact of this has the potential to contribute to early or avoidable mortality. Focused LeDeR reviews are graded in two areas, in line with the LeDeR Policy (2021), the overall quality of care the person received and the availability and effectiveness of services. The score is an overall judgement on the care the person received, it is not reflective of one service but of all the services who worked with the person as an entirety.

The breakdown of the grading can be found in *Appendix I*. Where 1 is poor care and 6 is excellent care.

Context for grading of care 2023/24 shown in figure 15

Scoring of 1 for Quality of Care: This relates to concerns of a late cancer diagnosis, Mental Capacity Act omissions and suboptimal end of life care.

Scoring of 2 for Quality of Care: This relates to concerns of late cancer diagnosis, epilepsy concerns, diagnostic overshadowing and concerns around the deteriorating patient.

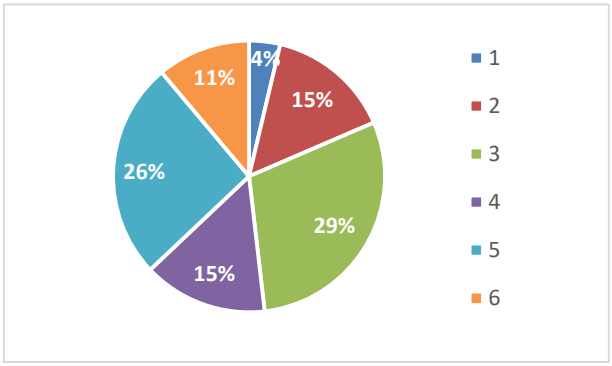


Figure 15. Grading of care

Scoring of 6 is outstanding and care we wish to celebrate and learn from; this was demonstrated by the following: Outstanding Positive Behaviour Support (PBS), dignified and consistent end of life care, effective care, and support with regards to intersectionality, and religious and cultural needs. Optimal adult social care package meeting the needs of individuals in a person-centred way. Care co-ordination – calling upon clinicians who specialise in the field for advice (palliative care Loros consultant) and family involvement.

Grading of availability and effectiveness of services.

Overall, two thirds of care was found to be satisfactory or good which is in keeping with last year; this presents LLR with continued opportunity for improvement.

Some examples of positive learning related to **availability and effectiveness of services:**

- Proactive, consistent preventative healthcare including LD AHCs, vaccinations, screening and early diagnosis and intervention.
- GP providing dignified consistent care and treatment. Carers supporting to live a longer healthier life even with co-morbidities by supporting to reduce BMI out of the obese range, also giving more independence back. STOMP medication stopped as care staff were able to proactively manage behaviours so effectively. Person centred care.

As only focused reviews are graded and by nature many cases that require the initial review have fewer areas of concern, a level of caution is required.

Six Key Themes

All learning from LeDeR is themed, as per the LeDeR policy (2021). The requirements have changed this year, moving from 6 to 10 themes, making comparison challenging to the previous year.

In LLR, *Table 1. 10 Key Themes - learning points* shows the number of actions (learning points) related to the 10 areas.

Theme	No. of learning points 22-23
Professional practice and provision of care	161
DNACPR recommendations and end of life care	64
Care Pathways	60
Family and carer awareness of available support	48
Safeguarding	24
Learning Disability Awareness	24
Deterioration	22
Training on specific conditions	12
Transition	10
Involving the Coroner	10
Grand Total	**426**

Table 1. 10 Key Themes - learning points

The area of highest concentration is with regards to professional practice and provision of care. This is broken down again in *Table 2. Sub-themes - learning points*. *(Please note only top 10 sub themes included.)*

Sub theme	No. of learning points
Person Centred Care	49
Deteriorating Patient	29
Care Planning	29
Reasonable adjustments	27
Care Co-ordination	27
EoL	26
MCA	25
Referral	25
DNACPR	22
Safeguarding	20

Table 2. Sub-themes - learning points

Priority areas of learning

This section outlines the priority areas of learning from the LLR LeDeR reviews for the past year. The top 3 priority areas are; Person Centred Care, Deteriorating Patient and Care Planning, which are all different from previous years priority areas of learning *[End of Life Care, Care Co-Ordination, and Communication].* Person centred care reaching the top area of learning for LLR LeDeR is an outstanding achievement and one to be celebrated. There has been an increased focus on improving the care of the deteriorating patient which is still a high priority for the coming year. Some anonymised information formed from LLR LeDeR reviews have been included to aid learning and context shown below.

Person Centred Care

Learning [5]

"The team had made a number of attempts to carry out a telephone review but was unable to as every time he tried; the phone went unanswered. This is a common finding of LeDeR Reviews." [Epilepsy review].

"The lady had down's syndrome and dementia. Their carer was unable to provide medical history information at a planned appointment with the ophthalmologist to discuss her eye condition."

"She had autism and a LD with associated behaviours that challenge. Staff could understand, support and interpret her behaviours on a daily basis, which supported her to live as independently as possible. Changes in staffing and lack of continuity were very unsettling for her and resulted in deteriorating behaviour. This was to such a degree that it resulted in a lengthy hospital admission in an assessment and treatment hospital for almost 1yr. The importance of continuity of carers for those with autism and a LD is well known and should be acted upon."

Positive Practice [44]

"A gentleman with a severe LD and autism moved to a new residential care provider. Family had worries about the move. The care home accommodated the gentleman's family member to stay overnight to support him and the staff team. He settled very happily into his new home."

"It was acknowledged that they were coming to the end of their life, and they were supported to die at home. They had an advanced care plan describing their wants and wishes for the end of their life and this was explained in an easy read manner by the care home and GP. Their ReSPECT form and DNACPR were all explained to them, and they were able to be in control and supported in a personalised and dignified manner with the necessary reasonable adjustments provided."

"She really liked chocolate. Her niece made her snack boxes when she became bed bound. There would need to be 'timeout' chocolate bar in there, as they were her favourite. Often carers or family would get to her and she would be in bed covered in chocolate!"

"A 71yr old lady with a LD had always lived in the same residential home as her friend. When their former care home closed, they were both able to move to the same home with identical living arrangements."

Deteriorating Patient

Learning [26]

"A 58-year-old male with severe LD with many co-morbidities and vascular dementia. He had been experiencing significant weight increase and urinary tract infections for over 12 months, but concerns were not identified appropriately, leading to his rapid deterioration. Carers and professionals should be aware of the significant changes in an individual's presentation to ensure their health needs are addressed, this includes multi-disciplinary discussions and planning of care where appropriate."

"A 71-year-old female with a mild LD and many co-morbidities. Her physical health was declining in the past year, it would have been appropriate to support the discussions of advanced care planning, ReSPECT and DNACPR. This lady had a ReSPECT form only days before she sadly passed away. Those documents should be completed when the person is able to contribute ideally and there was ample opportunity for this prior to her becoming very unwell."

Positive Practice [3]

"A gentleman with a moderate LD, he had been refusing food and fluids for around 3 months and following best interest discussions had a PEG tube put in place, whilst he was in a position physically to be able to have the PEG procedure (i.e., was within healthy weight range and not experiencing malnourishment). The MCA was followed, and MDT working was excellent. The PEG went onto support him for many years as a back-up for nutritional support which continued to be an ongoing issue throughout the later years of his life. MDT included, ALN, hospital doctors and ward, LD SALT."

"She was admitted to the acute hospital following being found collapsed at home. The acute hospital identified a persistent and dropping low Hb and carried out an endoscopy and CT scan. This identified an oesophageal cancer. The hospital were thorough and the care was prompt, preventing any further delays for her."

Care Planning

Learning [16]

"A gentleman diagnosed with a moderate LD with complex physical and mental health issues and behaviours that challenge. Following abrupt move into a new care home, issues regarding provision of care were raised. LD professional stated that he was not receiving weekly weight checks and GP follow-ups were being missed. On one visit to the new home, it noted he was sitting alone at the dining table. His care plan stated he should be 1:1 at all times, and concerns that care plans were not being followed. A mattress (with alarm sensor) was not working."

Positive Practice [13]

"A female, who resided in a care home and had a mild LD, she was a wheelchair user and had a sight impairment. There is evidence that when she moved into a care home, she was overweight

but with support in the care home to make healthy food choices her weight returned to the healthy range. This also had a positive impact upon her diabetes and resulted in her no longer requiring insulin."

STOMP/STAMP

LLR LeDeR has seen a reduction in the prescribing of psychotropic medication with a STOMP/STAMP review. This is extremely positive and encouraging. In the previous year 28% of people had a STOMP/STAMP review and 27% did not, and no data was available for 45%. Due to more accurate data being available figure 16 shows a significant increase in the numbers of STOMP/STAMP reviews. This improvement reflects the hard work of our GP and Psychiatry colleagues and the STOMP/STAMP workstream.

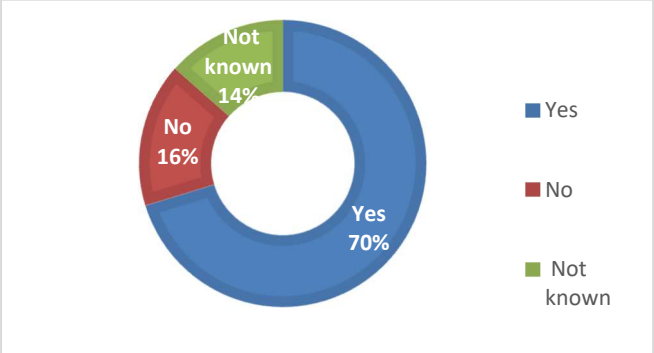


Figure 16. STOMP/STAMP review carried out for people on psychotropic medication at time of death.

Learning

- Although the long-term use of anti-psychotic medication is being used to manage symptoms with success. The long-term use of anti-psychotic medication had caused adverse effects to an individual resulting in Parkinsonism. Family felt they had not been made aware prior of the long-term side effects of prolonged use of anti-psychotic medication, and questioned had they known, could something have been done sooner, to prevent the Parkinsonism. A STOMP review would have been invaluable over the years to monitor this.

Positive Practice

- CRIST provided care and treatment in the community. This included functional analysis and PBS reducing behaviours that challenge and enabling him to communicate his wants and wishes in positive ways. As a result, he was not treated with medication for his behaviours, and he avoided a hospital admission.
- An older gentleman in his late 70s with a mild LD, originally from Uganda. His GP got to know him well and held a positive professional relationship with the home he resided in. As part of his review his diagnoses was checked and when it was found that there was no evidence of his psychosis and depression, he was titrated off his prescribed medications, in line with STOMP.

"During her hospital admission, her niece bought in a Mamma Mia DVD and portable DVD player with headphones so she could watch it in hospital. With the headphones on she couldn't hear herself so when she sang along, she got louder and louder!"

- A female with down's syndrome and behaviours that challenge was under LD Psychiatry team had regular STOMP reviews and evidence throughout her life of changes to medication to ensure antipsychotic medication was only given for a specific amount of time. In discharge letters good planning for GPs to follow instructions on how to reduce medication in the future was evident. The GP practice offered excellent reasonable adjustments with regards to blood taking with success.
- A gentleman with a mild LD and psychosis. Due to his chronic and enduring mental health needs he was prescribed psychotropic medication. The LD Consultant Psychiatrist reviewed his medication in line with STOMP over a long period of time to optimise the dosage; minimising side effects and optimising his mental health. A happy medium was found which he was stabilised on. Demonstrating person centred care and balancing his physical and mental wellbeing needs for optimal health.
- A male with a mild LD, autism and associated behaviours that challenge. He received PBS from CRIST, which successfully supported STOMP with the withdrawal of prescribed psychotropic medication, which he never went back on.

For the next several years:

- The Nice Guidance NG11 (2015) audit (conducted in 2021-22) action plan is ongoing.
- LPT have delivered a new service model offering Intensive Support underpinned by PBS principles, the service is called CRIST as previously mentioned.
- The STOMP forum is led by the Clinical Director to lead improvements around polypharmacy and pharmacological interventions.
- Sponsorship of the implementation of the role of the Advanced Clinical Practitioner, in line with building the right support and STOMP. The intention is to recruit to in the next financial year.

Behaviours that Challenge

LLR LeDeR has seen a significant increase in the number of people who had a PBS plan where behaviours that challenge were present than those who did not have a PBS plan. Last year 37% of people had a PBS plan and 63% did not. This is extremely positive and demonstrates the enormous amount of work from the PBS practitioners and LD Services. It should also be noted that not all behaviours that challenge present risks and support needs that require PBS input.

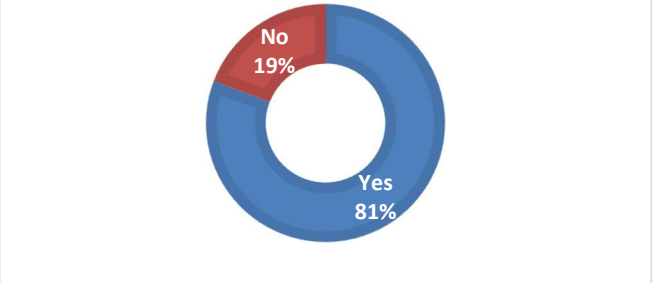


Figure 17. People with challenging behaviour who had a PBS plan in place.

The LLR LeDeR Programme recommends further commitment to PBS work and increasing the knowledge across LLR of behaviours that challenge and the importance of meeting people's communication needs on improving care experiences and reducing admission to hospital. LPT have recruited 2 x Advance

Clinical Practitioner positions, 1 x role is for physical health and on 1 x role is for PBS and mental health.

Learning

A lady in her 70s with a mild LD and behaviours that challenge. Notice was served by her residential placement provider (an older persons care home) due to her displaying behaviours that challenged. She was moved to a residential care home for people with LDs and was served notice again only 3 days later. This was due to staff not being aware of the extent of the behaviours, being inexperienced in managing behaviours that challenged and not having safe staffing numbers to ensure the safety of the lady and other residents. The outcome of this was that the lady was not adequately supported during this move by an experienced staff team and consequently her anxieties increased. She then had to experience a further move to another residential care home. Fortunately, this placement was able to manage and support the lady to meet her needs and positively support the behaviours she displayed that were challenging.

Positive Practice

A male in his 50s with a mild LD, autism, and behaviours that challenge. Due to his unpredictable and occasional violent behaviour, it was not safe for him to remain living at his care home. The staff and service were creative in their approach and repurposed a flat within the care home to provide a safer option for him. He could still access the communal areas where 26 other residents socialised but have his own space with 1:1 support when he needed it or became overwhelmed. This provided personalised care and support to live independently with dignity and prevented readmission to a hospital assessment and treatment unit.

Repeated hospital admission at End of Life

Last year the number of people who experienced repeated hospital admissions at the end of their life was 54%, this has reduced to 19% this year. Through the LDA Collaborative and SHaW, LLR have been determinedly working to improve end of life care and respond to identified concerns about the care provided to people with a LD when their health is deteriorating. These impressive results provide part of a body of evidence demonstrating improved outcomes in an area that is often difficult to quantify. It is known that people with a LD can find hospital admissions particularly stressful and unpleasant. During a person's end of life care repeated hospital admissions should be avoided where possible and appropriate. It is recognised that there may often be some requirement for hospital admission, however repeated admissions should be avoided.

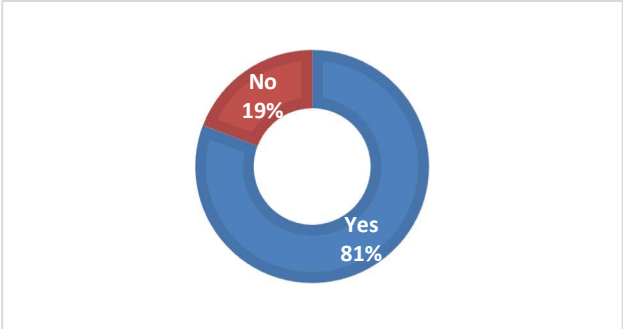


Figure 18. People on EoL pathway who had repeat hospital admissions.

It has been observed through the LeDeR governance panels that the lack of 'specialised nursing care provision for people with a LD' is showing an impact. The programme has heard about the care of some people with a LD who experience behaviours that challenge and have physical healthcare needs and not receiving sufficient specialist nursing care that includes both behavioural care and management, and nursing care. Some people are having either their behavioural and LD needs met, or their nursing care needs met. This is consistent with the findings from the previous year.

Without care provision skilled in both of these areas, we will continue to see people with a LD having avoidable and repeated hospital admissions, becoming 'stuck' in hospital care having had notice issued on their placement, and frustrated care providers unable to provide the home for life and death that people with a LD and autistic people deserve.

This year the local focused priority review area for LLR LeDeR was "e*ither concerns around the deteriorating patient OR concerns around the EOL care the person received."* Which can be found later in this report.

LeDeR continues to be influential and a focal point in steering the LDA Health Inequalities group and the SHaW (previously known as the deteriorating patient) subgroups agendas. The LeDeR themes influence the future of these working groups across the system to implement the learning into action and improvements.

An example of the work this year has seen the successful sign off and implementation of the local accessible end of life care plan and the LDA Collaborative's focus on the deteriorating patient for this year across the following themes:

- Weight management, improving access to weighing equipment and nutrition and hydration.
- Improving the outcomes for people with LD and epilepsy benchmarking.
- The role out of LD specific training to care homes on recognising the deteriorating person, RESTORE2 mini and SBARD.
- Venepuncture care and provision.
- Aspiration pneumonia.
- Health Equity Lead Nurse post established.
- Commencement of Skills for Health competency framework for CNLD.
- Implementation of adapted EoL care plan.

Learning disabilities and autism collaborative – LLR HWP (leicesterleicestershireandrutlandhwp.uk)

Safeguarding

LLR LeDeR continue to work closely with the LLR safeguarding teams. Where a LeDeR review and Safeguarding Adults review is being conducted at the same time, the Safeguarding Adults team lead and carry out necessary communications specifically to family members, this is also on behalf of the LeDeR Team. This enables collaborative approaches, reducing stress, upset and

inconvenience to families. A memorandum of understanding has been agreed to formalise this process. During the coming year there will be further progress as the safeguarding elements in LeDeR are strengthened through this partnership.

Preventative Healthcare

Venepuncture

Venepuncture is one of easiest and the most widely used medical tests to diagnose and manage people's health. However, this can be extremely challenging if a person is not compliant with the blood taking procedure.

Learning

*"*A gentleman with a moderate LD and Fragile X Syndrome and behaviours that challenge. The Community LD service requested that a LD AHC and blood tests be arranged for him. He did not receive the tests for around 6 months and missed his LD AHC due to being changed GP practice during this time. General oversight of his care was lacking. The gentleman was displaying poor health and required his bloods to have been monitored appropriately in line with his care plan for his blood conditions, hyperthyroidism, and metabolic monitoring."

Positive Practice

"The GP practice offered excellent reasonable adjustments for blood taking, providing a person-centred approach offering reasonable adjustments, graded exposure, and opportunity to attend ad hoc as she was more compliant on some days that others which was difficult to predict. She successfully had her blood test."

LPT LD service has been successful with a grant to run a pilot scheme consisting of a LD Phlebotomy team to offer blood taking to those individuals with a LD unable to use generic phlebotomy services. A nurse and nursing associate will be working in the team during 2024-2025 and operating using the legal frameworks where intervention is likely to demand a more restrictive intervention than has been used before. The team endeavour to have a desensitisation programme, a protocol and risk assessment for optimising successful venepuncture and a sedation outpatients' pathway. This is an exciting venture that the team have not seen replicated in other areas of the country.

Vaccinations

There are preventative healthcare measures that are available on rolling NHS programmes, the aim is to prevent avoidable mortality through vaccinations and screening for early detection of changes. Everyone should be given the opportunity to partake in and be aware of the available programmes. There are a number of factors that can affect engagement and reduce opportunities for vaccinations for people with a LD and autistic people and therefore, reasonable adjustments are often required.

Flu Vaccine

People with a LD, their family carers and paid supporters are entitled to a free flu vaccination. The person's choice, history and consent are important. Respiratory illness remains the leading cause of death for people with a LD in LLR. It is also known that if those around the person are vaccinated against flu, then the person themselves are less likely to contract it. Reasonable adjustments are pivotal in increasing the uptake of the flu vaccination for people, where required the nasal vaccine can be considered as an alternative with the planning and agreement of the GP practice, the person and their support network. In LLR it is encouraging that 77% of people had their flu vaccine in the last year of life, which is marginally higher than in the previous year [70%], this should continue to be encouraged and increased. People should also be encouraged to attend their LD AHCs where further reasonable adjustments and opportunities can be agreed, recorded and shared with other care providers.

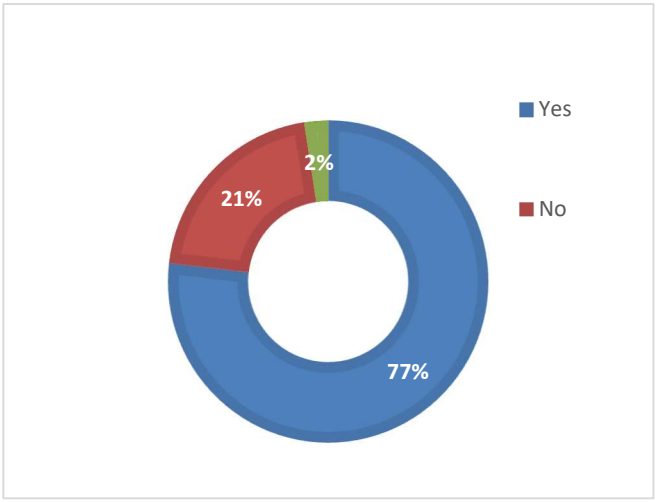
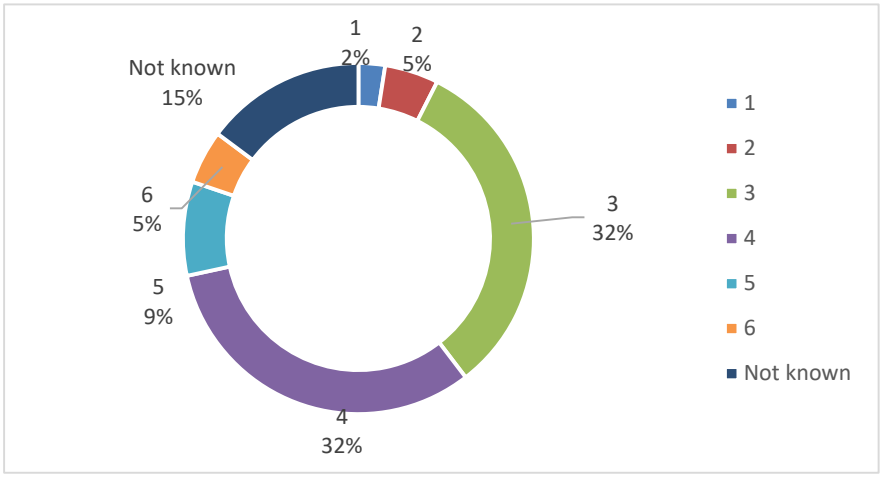


Figure 19. Flu jabs received.

Covid Vaccine

This year there have been no deaths from COVID-19.

The chart shows that most people have had either 3 or 4 COVID vaccines, with no-one reporting to have had zero vaccines. It is noted that there is a group of people this information is unknown. It is encouraging that more people this year have had 5 or 6 COVID vaccines and fewer people have had 1 or 2.



LPT have now stopped the specialist LD and autism covid vaccination teams, in line with demand ongoing scrutiny and intervention to increase vaccination rates is essential.

"He was "music mad" and would listen to one of the records from his huge collection".

Screening

Cancer screening is an extremely valuable and important preventative healthcare measure. However, there remain some barriers to access and even more so for people with a LD and autistic people.

Cervical Screening

In 2023-24, LLR LeDeR saw for those eligible for cervical screening only 9% of people attended, this is significantly less than last year. When comparing to the general population this is considerably lower (with cervical screening uptake generally being over 60% for the general population). Cervical screening is known to be one of the more challenging of the screening services offered in terms of uptake, due to the intimate nature. Nevertheless, people should always be offered the appointment, never be removed from the screening register due to having a LD or autism, and if required should be offered alternative checks such as, abdominal checks and menstrual tracking.

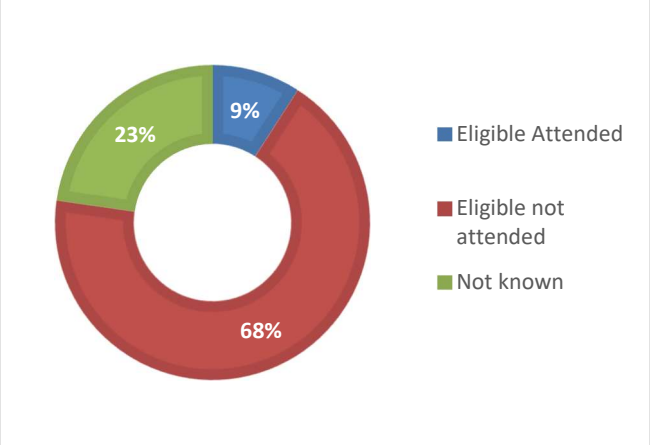


Figure 21. Cervical cancer screening attended (Where eligible)

The LD PCLN team planned and co-ordinated a specialist project on cervical screening to increase the uptake for people with a LD in LLR. The team were successful in securing funding for the project from the LLR Cancer Screening Network. The initial project was due to run in March 2020, however due to the Covid-19 pandemic the work was suspended for two years.

The collaborative work between LPT and UHL was a complete success, yielding 100% success rate for every person on the day. The nurses have since reflected upon this session, the tilt chair was of exceptional benefit for all who attended for cervical screening, and it is hoped that this chair can be purchased and used for primary care next year. The detail of person-centred care and reasonable adjustments, including transport was found to be of most benefit.

The team are considering locations nearer to the individuals as well as plans to run regular clinics for non-attenders. The LD PCLN team have also worked collaboratively with one Primary Care Network in LLR who have put forward a proposal to run an enhanced service for LD specialist cervical screening clinics into 2024-2025. The team are considering local data analysis and impact going forward into the next financial year. Lastly, some exceptional work was the myth busting videos creating to encourage and support people with a LD and autistic people to attend for their cervical screening.

"Her carer had known her for nearly 20 years and said that she was magic and an incredibly special lady."

Cervical Screening Myth Busting Videos:

[Cervical screening myth busting: Question and answer (youtube.com)]

[Cervical screening myth busting: Cali's story (youtube.com)]

Press release can be found here:

[leicspart.nhs.uk/wp-content/uploads/2024/07/BBC-Radio-Leic-090724-Cervical-screening.m4a]

Breast Screening

In 2023-24, LLR LeDeR saw 33% of people eligible for breast screening attended, when comparing to the general population this is significantly low, with breast screening uptake being in the range of over 60%. Breast screening along with breast checking are imperative for preventative healthcare and people should be adequately supported with relevant reasonable adjustments, reminders and prompts where required. The easy read video is still available on the internet to support people with LD and autism on breast screening, that was developed by LLR and should be used and promoted.

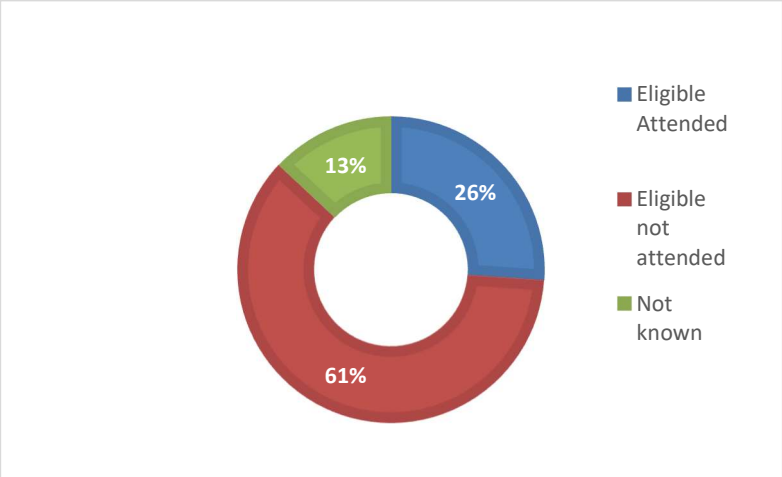


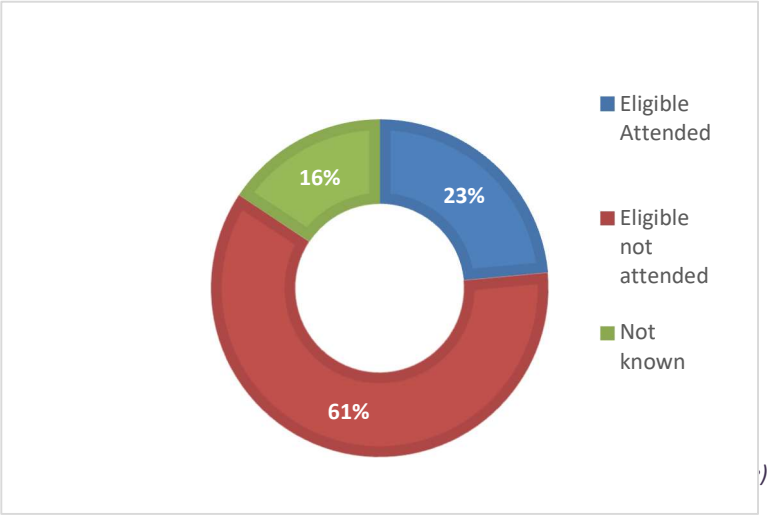
Figure 22. Breast screening attended (where eligible)

[https://www.youtube.com/watch?v=HphkoUbfNQQ]

As part of the drive to increase equality for people with a LD, the LD PCLN team are working with the Breast Screening Service in LLR. The aim is to improve access by ensuring that the breast screening service are aware of individuals that have a LD and can offer them appointments at their Equality Access Clinic by using accessible letters that are more easily understood. The AHC template has also been revised and now alongside all screening questions are the links for the easy read information which can be printed and given during the check.

Bowel Screening

This year LLR LeDeR has seen 23% of eligible people, attend for their bowel screening appointment, which is significantly low when compared to the general population of more than 70%. Bowel screening usually yields one of the highest attendance rates due to its less invasive nature and we would be expecting this figure to rise. There has been some encouraging



positive practice seen this year in LLR LeDeR with regards to supporting people with a LD to respond to the bowel screening invitation and on occasions work has been undertaken to support people in their best interests where this has been deemed necessary and appropriate. This will be continued into the next financial year.

Abdominal Aortic Aneurysm (AAA) Screening

AAA screening demonstrates that approximately a third [32%] of the eligible people through the LeDeR programme are attending compared to 75% of the general population of LLR. Further work is required to address this inequality.

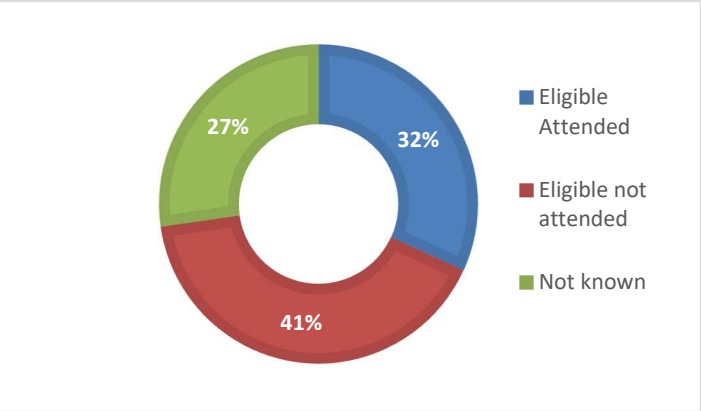


Figure 24. AAA screening attended (where eligible)

LD Annual Health Check

The past year has seen the highest achievement in the uptake of LD AHCs in LLR with just over 80%, which is reflected in LeDeR too. The GP practices, LD PCLN team and the newly appointed Health Equity Lead this year, as well as others including people with a LD and their families, friends and carers should be commended on the success in driving forward this agenda.

LLR is now second in the Midlands (and in the top ten in England) in terms of the number of AHCs completed. Two years ago, LLR was one of the lowest performing areas in the country.

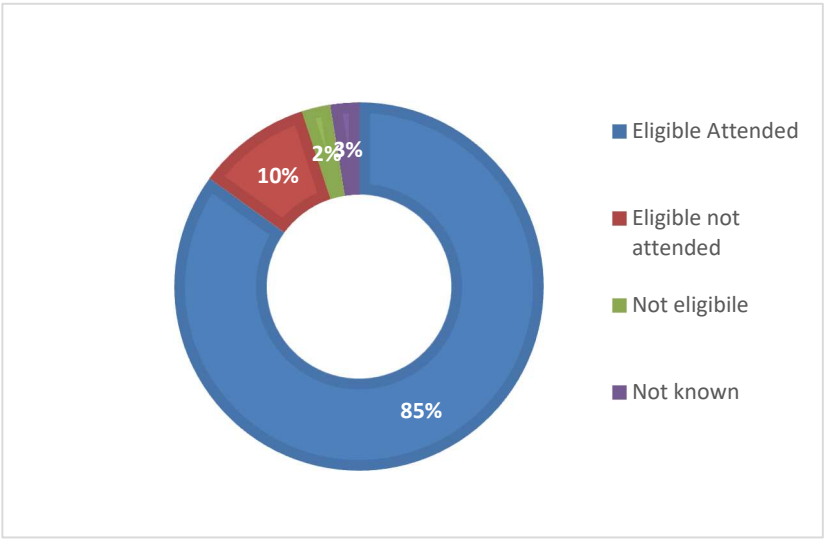


Figure 25. LD Annual Health check attendance

LD PCLNs, offer regular support and training on AHCs for primary care, social care partners and care providers, including GP practices, to improve access to health care and reduce health inequalities for people with a LD.

The team are currently running a pilot project to increase the AHC uptake for those people who haven't had a health check in 2 years or who have complex needs requiring reasonable adjustment over and above what the GP practice can offer.

Thematic Analysis

Thematic analysis is a qualitative research method that can be widely used across a range of epistemologies and research questions. Lincoln and Guba's (1985) criteria for trustworthiness during each phase of thematic analysis is widely used and often viewed as the "gold standard" for qualitative research. This ensures reliability, credibility and trustworthiness in our analysis process. This framework has been adopted in LLR for the purposes of the LeDeR learning into action and demonstrates the systematic structure of thematic analysis undertaken for the LeDeR reviews in LLR.

There were four areas of focus for LLR LeDeR during 2023 – 2024, which were:

- Concerns around the deteriorating patient and/or concerns around end-of-life care – *local priority focused review area agreed at Steering Group.*
- Leading a Safe Programme – Deaths of those living in Care Homes.
- Weight.
- MCA.

Concerns around the deteriorating patient and/or Concerns around end-of-life care

The Royal College of Nursing (2024) describes a deteriorating patient as someone whose medical condition is worsening or declining. This occurs in a variety of ways and settings and manifests through worsening vital signs, increasing symptoms, or decline in overall health.

A person who is coming to the end of their life, usually refers to the last year of life, although for some people this will be significantly shorter. **RCN 2024**

How we provide care and treatment is different to the deteriorating patient and the dying patient. The LLR LeDeR programme wanted to explore this further, and it was agreed that the local focused priority review area would concentrate on the deteriorating patient and concerns around end of life care, with a themed governance panel held at the end of the year. Below outlines the top areas of learning and themes that were identified in LLR.

Top 3 Areas of Concern

1. Lack of specialised nursing care provision for people with a LD.
2. Implementation of Advanced Care Planning.
3. Dying in chosen place of death.

Top 3 Positive

1. Nationally 59% of deaths of people with LD occurred in hospital, locally this is 50%.
2. Improvements in following Advanced Care Plan.
3. Comfortable care at home for active End of Life care is excellent.

ReSPECT

Findings show that there are more concerns with the ReSPECT process when compared with positive practice in this area. The findings can be found below.

- Bystander CPR – carers not instigating or performing CPR.
- Unable to locate ReSPECT form when required in an emergency (care home).
- Completing the form when the person is able to contribute their wishes and are not too unwell.
- Awareness of when to instigate ReSPECT discussions.
- The need to consider the completion of a valid ReSPECT form before a person is identified as actively dying, as opposed to a rapid completion in emergency situations, for examples urgent admission areas.

Mental Capacity Act

- Being discharged home to die at end of life (from hospital) was delayed due to no NOK and delays from IMCA. The ReSPECT form and EoL plans were completed by the GP, but no IMCA had been involved in the process.
- Confusion over NOK legal basis and best practice with regard to MCA.
- Delays in primary care resulting in the person's acute admission and an MCA being completed under an emergency or urgent situation.

Advanced Care Planning

- The end of life wishes of people with a LD are being missed because the information is unknown before the person has passed away.
- People with a LD are not being supported to visit their loved ones they have lost at their grave or memorial place.
- Advanced care plans and ReSPECT forms are highly sensitive. But they open the opportunity to reflect on life and fulfil things before end of life for people. They must be prioritised for people with a LD in line with their wishes, beliefs and values.

Dying in Chosen Place of Death

- There is an identified lack of specialised nursing care provision for people with a LD.
- Reasons that people with a LD required this service included:
    - People with behaviours that challenge as well as nursing care needs.
    - LD Residential care not equipped for nursing care and wraparound care not co-ordinated.
    - Equipment concerns and delays.
    - Building/stairs and general infrastructure.
    - Increase in staffing requirements.
    - Tissue viability and pressure ulcer care and prevention.
- People with a LD are living longer with more complex health conditions. Associated decline in communication and cognition can occur. When a person moves out of their home, they

often encounter situations where the people caring for them cannot interpret their communication and their pain, at a time they are at their most vulnerable.

Pain

People with a LD are at increased risk of communication of pain being misinterpreted or missed altogether, and it is essential to safeguard against this. There are communication tools/passports and a DISDAT (Disability distress assessment tool) that are readily available for people with a LD. Care providers, particularly those who are either not specialist in the field of LD or who do not know the person well, and other services involved in their care must ensure that the communication needs and most importantly how pain is communicated by the person are known, recorded, prioritised and shared. A priority must be with regard to those individuals who are moved away from their care setting into nursing care providers due to end of life care needs. This information must be shared through clinical records, communication passports and the Reasonable Adjustment Digital Flag.

It is imperative to really consider if moving people with a LD out of their homes at the end of their life into nursing care is the best option for them when weighing up all of the information we now know.

Talking about the end-of-life moments

The death of a young man was understandably very distressing for his family. Governance panel members wanted to raise that there are areas of end-of-life and death that should be talked openly about.

What to expect and how to cope as well as seeing a loved one pass away is a long-lasting event and memory. One to be held in the upmost support, care and compassion possible. Panel members felt this conversation requires space on the LeDeR learning into action.

Deteriorating Patient

- Recognising the signs of deterioration in people with a LD.
- Wider use of Restore2.
- Knowing the person well makes a difference. The 3 areas of importance in the deteriorating patient:
    - Medical assessment and observations alongside
    - Knowing the patient's usual baseline when they are well and
    - Following the communication passport and DISDAT.

All 3 should be implemented at the same time. This underpins the value and importance of the MDT.

- Professionals ensuring, they are actively listening to the concerns of the carers and support workers of people with a LD.
- Diagnostic overshadowing remains an issue.
- Increasing skills and knowledge of LDA community services.

Positive Practice

- The person had no NOK, so a referral was made to Age UK Advocacy Service who provided her with an advocate to support with difficult decisions.
- Care provider ensured that familiar staff visited her regularly in hospital. Her favourite carer happened to spend the day with her before she passed away. It would have been her choice to see that staff member. Consistency makes a difference in EoL care.
- The Accessible Advance Care Plan was published last year.
- In UHL it has been agreed that the deaths of 20 patients will be reviewed using the same criteria as NACEL (National Audit for Care at End of Life).

Leading a Safe Programme

Deaths of those living in Residential Care [Leicestershire]

The thematic analysis of care home deaths aimed to determine if there were any trends in the deaths of care home residents. This included those who died either in hospital or in their care home. Anecdotal evidence and concerns raised by our team of reviewers and at governance panels prompted us to investigate further. Areas of feedback from reviews included: Patterns of high mortality rates in specific care homes; Trends in unexpected deaths; Low staffing levels; Inadequate staff training; Funding issues; Poor discharge planning; If individuals with LD were unable to have their preferred place of death (PPD) met and Care providers' hesitation to offer end-of-life care due to external support deficits and confidence in providing this care.

Initially, 65 reviews were identified, out of which 33 completed reviews were relevant to our Leicestershire County project. An initial analysis was conducted to determine if any themes corroborated the concerns feedback; however, none were found. Consequently, a more extensive scoping process was undertaken to examine all recommendations and themes from the 33 completed reviews from Jan 2021 – Dec 2022.

The group consisted of 16 females and 17 males. Out of these, 31 individuals were of White British heritage, and 2 were from an Asian heritage. The age range spanned from 39 to 90 years. It was observed that the average age at death in care homes was 74, while in hospitals it was 60.5. Regarding the place of death, 17 individuals passed away in care homes, and 16 in hospitals.

In the 33 reviews conducted, 15 were initial and 18 were follow-up reviews. None received a grade of 1 or 2 for effectiveness and quality of care.

In relation to advanced care planning (ACP) and PPD being met it was identified that there was insufficient information contained in the review for 9 people to establish if their preferred place of

death was met. PPD was met for 12 people, PPD not met for 4 people who were too unstable to transfer home and No ACP in place for 8 people.

In line with the latest LLR LeDeR report, the top cause of death of people who lived in care homes was respiratory disease, followed by cardiovascular, then neurological and cancer.

The top 2 good practice themes identified from 46 examples of good practice were related to Professional practice and provision of care and ReSPECT/End of life care. Examples included "exceptional end of life care… he died with dignity at home "In relation to 49 issues identified for learning into action, the top 2 were Professional practice and provision of care and the deteriorating patient. Examples include lack of recognition of the dying patient and missed opportunities to develop ACP's and /or ReSPECT discussion or forms when people were clearly approaching their final months or years.

Weight

The project was to find out what affect poor weight management has on the outcomes of people with a LD within LLR. To explore this further we looked at the deaths which occurred between April 2022 and April 2023.

Within LLR there were 158 deaths reviewed between this period. Nearly 50% of people who died during this period were overweight or obese.

Some people with a severe LD were found to be underweight, although this was found to be more common for people with a severe LD, it is not typical and warrants suspicion and intervention as it has serious implications for the person's health and is a key indicator of the deteriorating and dying patient.
The key findings from the deaths related to those in the overweight or obese BMI categories:

- Increase in diabetes diagnosis.
- BMI adjustments for those from an ethnic diverse background were not always considered.
- The Mental Capacity Act (2005) was not consistently implemented.
- An absence of early intervention.

The top 3 comorbidities identified for those overweight or obese were, coronary artery disease and strokes, type 2 diabetes, and hypertension.

Overall, 10% of deaths were found to be potentially avoidable. The death was considered as being potentially avoidable where the deteriorating patient was identified and intervention for weight was too late. Over half of individuals lived within paid care settings.

Whilst there have been some good examples of positive management of weight, there are still common themes and poor health outcomes for individuals with a LD being identified. These included:

- Failure to make reasonable adjustments.

- Diagnostic overshadowing.
- Inadequate training for staff.
- Poor coordination of care.
- Lack of implementation of the Mental Capacity Act (2005).

The LDA Collaborative have weight management as a key priority area of focus and continue to take on further work in this area in 2024-2025. The LD Strategic Dietician is a key role and continues to evidence what this means and how this can be improved going forward.

The Mental Capacity Act

As mentioned in the statement at the beginning of this report, the system in LLR continues to be unsuccessful in the correct application of the Mental Capacity Act (MCA) (2005), in practise, for people with a LD and Autistic people. All time learning from LeDeR was carried out to identify the areas of the MCA that seem to be the most challenged in the system.

1. Instigating the MCA. We most often see that the person's capacity has come into question, however the decision maker has not initiated the legal framework.
2. Record keeping and documentation issues. This includes demonstrating the workings out and how the conclusions have been drawn through the steps of the MCA.
3. Procedural issues. This includes for example lack of family involvement in best interest meetings and recommending covert medication without following MCA procedure and documenting.
4. Not following what has been agreed from the MCA and in the person's best interest. This includes for example, family not implementing the medication changes that were agreed, a care provider not carrying out the agreed steps to support someone to leave their bedroom despite soiled bedding, and the MDT not coming together when the best interest agreement is not being implemented to review and make another plan.
5. Was not brought safeguards. We often see that someone is marked as having DNA'd (Did not attend) their appointment when they would not have been able to get to the appointment without the care of someone else. Due to incorrect documentation, was not brought safeguards are not being implemented.
6. Restrictive intervention. There is a lack of process and understanding of how to support someone with medical procedures when more restrictive measures are indicated under the MCA.

There are certainly areas of positive practice with the MCA, but the learning at this stage far outweighs the positive practice.

"She loved having nice clothes and she had beautiful outfits and wore these with bracelets and necklaces. She had a great collection of them and wouldn't leave the home without a necklace and a bracelet."

Autism

This year there were only 2 deaths of autistic people completed in the LLR LeDeR Programme. Whilst in keeping with national reports of the response from other systems this is concerning. The notifications of deaths of autistic people must be a priority and LLR LeDeR have set a quality improvement project on increasing the notifications of the deaths of autistic people in LLR to the LeDeR Programme. Nationally the NDOO (National Data Opt Out) has been amended, so that LeDeR reviews could be conducted for everyone who is in scope for LeDeR and for whom a notification is received. This exemption has now been granted which means that LeDeR no longer needs to enforce the NDOO and therefore, the notifications received to LLR LeDeR is hoped to increase due to this.

In total there were reviews of two autistic people's deaths completed in LLR LeDeR, both individuals were male, there have been no notifications of females. Areas of learning are highlighted below from the LeDeR Governance Panel members.

- Improving the understanding of autism across the whole of LLR health and care and consequently supports in its entirety the roll out of the Oliver McGowan training.
- Concerns with regards to identifying the person has autism and the required reasonable adjustments.
- The importance of post diagnostic support services.
- The mental and physical health of autistic people is paramount. There is a call for an autism register and autism health check.
- The importance of applying reasonable adjustments under the legal obligations of the Equality Act (2010). Services must be reminded that this is the law and their duties to provide this.

Since the inclusion of deaths of autistic people to the LeDeR programme, the LeDeR team have reflected on the first LeDeR suicide death. The LeDeR team have implemented debriefing and restorative supervision in response to this to ensure the well being of the LeDeR reviewers are upheld.

LLR LeDeR universally supports the introduction of the reasonable adjustment flag. This elevates the importance of the Equality Act (2010) and will raise awareness of the needs of both autistic people and people with LD, particularly when using mainstream services.

"He was a happy soul who held positive relationships with everyone that had the pleasure of meeting him."

Learning Disability Child Death Reviews

Definition:
Individuals with a LD are those who have:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- A significantly reduced ability to cope independently (impaired adaptive or social functioning), and
- Which is apparent before adulthood is reached and has a lasting effect on development.

Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) Policy 2021

LLR CDOP LeDeR Themed Review

Deaths of all people with LD aged 18 years and over are reviewed as part of LeDeR Programme, aiming to identify learning to reduce the increased mortality and morbidity rates seen for this population. In 2023, LeDeR stopped reviewing the deaths of children with a LD under 18 years of age due to duplication between LeDeR & CDOP. In LLR, it was agreed that we continue to work closely together and this is now achieved through this annual themed review. During 2023-24, 5 case reviews were completed for children with a LD who had died. A review group was convened with representation from Public Health, Childrens Social Care, UHL, LPT, ICB and the LeDeR Programme to look at these cases collectively, identify themes and learning, and to generate actions.

Of the 5 cases:

The most common category for cause of death was:

- Chromosomal, genetic or congenital anomalies (60%) – identical to 2022/23 review.
- Other categories included acute or chronic medical conditions and trauma/other external factors.

- Modifiable factors were identified in 2 cases.
- Positive aspects of service delivery were noted in 1 case.
- Mean age at death was 12.4 years (11-14 yrs)
- 80% were on the GP Practice LD Register (compared to none of the 10 cases in 2022/23).

Key learning themes identified during the 2023-24 review

	Communication. - Reasonable adjustments in communication (including use of interpreters) should be made by all agencies. - Hearing the voice of families, which is key to providing safe and effective patient care for children and young people with learning disabilities. Language barriers, diagnostic overshadowing and professional assumptions can all inhibit this.
	Prescriptions - Where possible, systems should be put in place to support families of children with complex needs to access repeat prescriptions in a timely way.
	Advanced Care Planning. - When done well, this ensures high quality support and allows family wishes to be followed. - Hospital Passports are a valuable tool for children and young people with a learning disability, to ensure they are appropriately supported in all healthcare settings.
	Challenges of reviewing deaths when children die abroad. - Guidance is available on how to obtain information for child death reviews. - Advice for child travellers is also available and should be shared with families considering travelling overseas

Recommendations:

1. Hospital passports to support communication and planning.

Going into hospital can be a worrying time for children and young people with a learning disability, and for their families. This can be further heightened around the time young people are transitioning from paediatric to adult services. Hospital passports are one way to help prepare for a hospital admission, and to ensure that services know what reasonable adjustments are required. They can also be used to support transition from paediatric to adult services.

- Services should be aware of Hospital Passport templates that they can share with families of children and young people. The use of Hospital Passports for children, young people and adults with a Learning Disability or Autism should be routinely embedded in all healthcare settings.
- Within UHL, all people with a Learning Disability should be 'flagged' on record systems, to ensure that they are known and reasonable adjustments can be provided.
- Those aged 18yrs or more can also be supported by the Learning Disability Acute Liaison Nurse Team within the hospital setting.

2. Prescriptions for children with complex medical needs

Children and young people with complex neurodisability may be on a significant number of medications, some of which may have particular requirements in terms of manufacturing, order and preparation time and availability. Mechanisms should be in place to support families

wherever possible with ordering repeat prescriptions in a timely way, particularly in relation to critical medication where delays in obtaining repeat prescriptions may lead to an increase in symptoms such as seizures.

3. Mortality reviews for when children, young people and adults die abroad

The death of a child, young person or adult abroad can present very significant challenges for families in terms of accessing care and support, and for gathering of information around the circumstances of death.

Services should ensure that if families are planning to travel abroad with children who have complex health needs, that they are signposted to information and guidance, and know how to access medical support whilst travelling.

Actions:

- For the use of hospital passports to be fully embedded across LLR for children, young people and adults with a Learning Disability
- For LLR CDOP to meet within the ICB Pharmacy team to share learning and review mechanisms for supporting families to access timely repeat prescriptions.
- For LLR CDOP to share with LLR LeDeR the resources and advice about how to gather mortality review information for deaths which occur overseas.
- For ongoing work to ensure all children and young people with a Learning Disability are on the GP Practice Learning Disability Register and offered annual health checks from 14 years.

"She kept busy at home by doing puzzles, sewing, making pom poms (which she made for everyone she knew!)".

Learning into Action

The learning into action for LLR LeDeR is reviewed on a quarterly basis and sent to the respective service provider in order for them to develop SMART actions. The service provider then reports back to the LeDeR steering group.

Top 3 Highlights of LLR LeDeR Learning that has been implemented:

GP and Primary Care

- Annual health checks - Significant improvement in uptake of across LLR – now focusing on quality with plans for quality improvement projects and continued integrated working GP practices and LD Primary Care Liaison Nurse Team.
- Blood taking in patients with LD – Launch of pilot scheme – a patient centred pathway to facilitate better attempts at blood taking in the community in patients who to date have been unable to have one. The aim being to improve disease detection and prevention and reduce morbidity and mortality.
- LDA Primary Care Champions – establishing a champion in each GP Practice across LLR – through work being undertaken to launch our "LD Friendly Practice" Award scheme.
- End of life care – new working group being established to focus on improving appropriate and timely use of the RESPECT process in patients with a LD and autistic people.

Leicestershire Partnership NHS Trust

- Introduction of GP friendly practice award to improve health outcomes for people with a learning disability living in LLR by supporting GP practices to improve care quality and patient experience. A self-assessment tool has been co-produced with people with lived experience and currently in the process of finalising a sensory environment check to support GP practices to understand how they can make their practices more accessible for people with physical and/or sensory needs.
- Two cervical screening videos have been created to break down barriers and support eligible people with learning disabilities and or autistic people. The videos were co-produced with people with lived experience. The videos have received positive feedback and are starting to be shared nationally.
- The core assessment in LPT Learning Disabilities is being reviewed and will now include discussion around DNACPR and ReSPECT this will enable quality conversations to discuss and reach a shared understanding of the person's current state of health and how it may change in the foreseeable future. And enable a conversation to break down barriers and give an opportunity to create a summary of personalised recommendations for a person's clinical care in a future emergency in which they do not have capacity to make or express choices.

- Aspiration Pneumonia risk assessment and care plan have been created. The development of a 1-page risk profile will support decision making around aspiration pneumonia diagnosis and treatment and enable people with this diagnosis to have personalised care, reasonable adjustments, identify higher risks and potentially identify appropriate treatment. Subsequently, having a protection plan will aim to minimise and /or manage the risk of developing aspiration pneumonia by identifying factors that increases the person's risk and management of the persons co-morbidities that could lead to an inappropriate diagnosis of aspiration pneumonia.

University Hospitals of Leicester NHS Trust

- Nearly 80% of UHL staff have now completed the OMMT online training which will help raise awareness of the need for reasonable adjustments.
- UHL have now recruited a Specialist LD Nurse to support children with LD and neurodiversity - this will improve the identification and management of children in transition.
- The LD Acute Liaison Team will be working more closely with the Epilepsy Specialist Nurse team to ensure any concerns regarding a patients epilepsy management are flagged to the Epilepsy team on discharge for follow up in the community.

Leicestershire County Council and Rutland

- Weights oversight - Care providers to understand and evidence in practice how they effectively support people with their weight management, know who they can refer to for concerns over weight management and how to make those referrals in a timely way, through training and awareness raising.
- Mental Capacity Act - Care providers to work within the Mental Capacity Act and the remit of their role. To have understanding about best interest decisions, contribute towards that decision where appropriate, working with the lead professional from health or social care, through awareness training and information.
- Reasonable adjustments - Care providers to understand reasonable adjustments and how to request this for people they support with LD and/or Autism. To make improvements through signposting care providers to LD and Autism LPT training to cover RESPECT, reasonable adjustments, hospital passports & STOMP, via Care Provider Bulletin and Provider Forums.

Leicester City Council

- Learning from LLR LeDeR has led to greater MDT working being progressed from an earlier point to bring professionals together with clear directives which are in the person's best interest for person centred support. Ensuring clearer communications between professionals.

- Continuing to ensure front line workers are striving to secure culturally appropriate placements. When sourcing placements the individual's culture, language and communication needs are identified to match to the best available care provider.
- Continuing early discussions with children's service partners and with families of the varying differences between adults and children's services to get the transition right. This includes greater involvement with workshops with families and carers earlier, under the PFA (preparing for Adulthood) agenda.

"She had a wonderfully close relationship with her mother and sister and people would talk about how much her face lit up every time she saw them".

Top Ten Learning into Action

This section aims to give a final top 10 summary learning into action points from LLR LeDeR Annual Report 2023 – 2024:

1. Report the deaths of those people autism (with or without a LD) to the LeDeR Programme.
2. Report the deaths of those from Leicester City and from diverse ethnic backgrounds to the LeDeR Programme.
3. The system continues to fail in the correct application of the Mental Capacity Act (MCA) (2005), in practise, for people with a LD and autistic people. Many professionals have legal obligations under the MCA, but they are not being fulfilled at a system level.
4. The practice of estimating someone's weight is a significant risk for people. People should know where to access suitable weighing equipment locally.
5. Clear plans should be created for every person with behaviour that challenges, highlighting the support they require and anticipating the support they are likely to need in the years ahead. This should be reflected in future commissioning considerations in LLR for provision of residential care for those with a LD, as physical health and nursing care needs increase particularly towards the end of their life.
6. Care providers must be competent and confident in talking about end-of-life matters and having these meaningful conversations at the right time. It is important to instigate Advanced Care Plans early enough.
7. Screening inequalities exist, and every effort should be made to improve the uptake. Barriers to non-invasive bowel screening should be rectified. Full implementation of the Reasonable Adjustment Digital Flag is recommended.
8. Better understanding of the STOMP/STAMP agenda across generic, physical, and mental health services.
9. Aspiration pneumonia happens as a consequence of a precipitating event. Identification of risk factors and ongoing management are key. This requires a multi-disciplinary approach.
10. There remains barriers to successful venepuncture for people with a learning disability, system challenges in limited availability and understanding of what can be done. This is especially for people who require a high level of reasonable adjustments to achieve successful blood test.

Achievements from Action set for 2023/24

Action Plan	Detail	Outcome	RAG Rating
LLR LeDeR projects for 2023 – 2024.	LLR LeDeR – the Mental Capacity Act through story telling. Leading a safe programme – Review of deaths of those who live in care homes. Weight Management – effects of poor weight management from the perspective of LLR LeDeR.	*The MCA analysis was instead completed as a themed analysis as we unpicked the systemic level of the issues and will continue to be a priority in the coming year.*	
Restorative Supervision	To balance the effects of compassion fatigue the LLR LeDeR Team will be engaging in 6 x restorative supervision sessions during 2023 – 2024.	*Two sessions complete, to continue into the next year.*	
Experts by experience:	Aim to ensure all the LLR LeDeR programme, boards, panels and where possible interviews are co-chaired by an EBE. This is from a strategy and planning perspective, creating the agenda and forming the drive and commitments of the programme.	Interview complete and LeDeR Lived Experience Partner recruited to. Aim for further recruitment and volunteer positions next year.	
Intersectionality	LLR LeDeR programme intends to embed intersectionality into each review, understanding local cultures, highlighting areas that are impactful for individuals on an individual and personable level, creating a diversity to the review, panels and discussions. This in turn will shape the steering group and confirm and challenge group. Accurate recording of the ethnicity of people with a LD and autistic people on electronic patient records is a priority to be addressed in LLR for next year.	*Complete and ongoing to improve year upon year.* *Remains a priority for the LDA Collaborative.*	
LeDeR Programme	To revise the membership and include more people and a wider audience i.e., registered managers of care provision for those with LDs or autistic people; mental health practitioners; Drug and Alcohol services; lay member to represent those from a diverse ethnic background etc. [List not exhaustive].	*Complete and ongoing to improve year upon year.*	

	To hold themed analysis: i. Diverse ethnic groups. ii. Autism only. iii. Local priority focused review area, which for LLR in 2023-2024 is 'concerns around end-of-life care and/or the deteriorating patient'.	*All complete apart from autism only. This is due to very few notifications to the LeDeR programme.*	
Steering Group	To hold themed steering groups directing the focus on learning into action and bringing all providers services together: LD AHCs. MCA. EOL. Weight. To receive bimonthly highlight reports from each provider service and to include positive practice. To better understand the learning into action progress more consistently.	*Some progress has been made but requires attention in the coming year. Particularly with regards to governance structure and feedback loop of learning into action.*	
Conducting High Quality LeDeR Reviews:	Receive a session on the 5 Why's is scheduled for the LLR LeDeR Team in May 2023.		
Autism	Support the introduction of the Autism register and autism AHC. To work with the Patient Safety Team and Learning from Deaths team in LPT to look to improve notifications of autistic people and improve overall governance structure of LLR LeDeR programme. Develop an autism only data collection, including additional relevant factors in autism only governance presentations.	*The biggest issue remains that notifications of the deaths of autistic people to the LeDeR programme are very low. Therefore, a QI project has now been set up for 2024-2025.*	
The LDA Collaborative focus through SHaW on the deteriorating patient workstream for next year is	Themes from the LLR LeDeR aspiration pneumonia analysis. EoL care for people with LD. Implementation of adapted EoL care plan.	Aspiration Pneumonia protection plan and journal article being designed and written. EOL care will be reviewed into 2024-25 as the thematic analysis is rolled out and onward plans and discussions are made.	

	Continuation of improving the outcomes for people with LD and epilepsy benchmarking - this is a 3-year plan. Continuation of the weight management and nutrition and hydration workstream. Trialling the new plans and service delivery on for venepuncture care and provision. Commencement of Skills for Health competency framework for CNLD. Preparing for emergencies and admissions to hospital.	Epilepsy training updated and epilepsy checklist being designed for roll out in 2025. The comprehensive weight management guide for all is in first draft to be published 2024-25. 19 accessible wheelchairs purchased for PCNs. Funding confirmed at the end of March 2024. To progress into 2024-25. In progress. In progress.	
Aristotle	To work with and alongside the Aristotle data system and teams utilising this database to reflect on findings from LeDeR.		
Health Equity and LD PCLN team Qi projects	Working with people with a LD in prisons ensuring the correct people are appropriately on the LD Register and appropriate LD AHC. To work with the Better Health group to work collaboratively on the health equity plan which LeDeR feeds into. Implement the transition age uptake of LD AHCs project [including CDOP analysis]. To implement the mobile vaccination unit for the coming year, to offer additional reasonable adjustments to access primary care; offer health promotion; screening and access to weighing and physical health checks.	This information has now been passed onto the forensic service.	

	Quality audit for LD AHCs.		
Hosting event and funding agreed.	LeDeR successfully bid and received funding for an event: 'A Journey Through Empathy and Emotional Awareness'		
Valued Star Award Winners	Valued Star – LLR LeDeR Team winners March 2023 [Award given in May 2023] LeDeR Team were nominated for the Excellence in Patient/Service User involvement July 2023		

New Actions for 2024 – 2025

Action	Detail	Outcome	RAG Rating
Life QI Improving the notifications of the deaths of autistic people to the LeDeR Programme.			
Establish LeDeR Confirm and Challenge Group.			
Audit of Learning into Action.			
High Level Action Plan created following announcement of NHS England.			
Support the roll out of the Reasonable Adjustment Digital Flag and system wide quality standards for improved LD response from all services and partnerships.			
Support the SHaW project plan.			

Appendix I

Governance Group

Grade of Care 1-6

Do we have enough information to make SMART recommendations?

If not what do we need to know?

Identify learning themes

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

NHS LeDeR – Learning from lives and deaths

Appendix 2

ANNUAL HEALTH CHECKS COMPLETION - MIDLANDS - 2023/2024

ICB or TCP Name	LD Register 22/23	LD Register 23/24	LD Register Increase %	Completed Health Checks	% Completed Health Checks
NHS Leicester, Leicestershire and Rutland ICB	4931	5233	6%	4325	82.6%
NHS Herefordshire and Worcestershire ICB	4183	4469	7%	3676	82.3%
NHS Staffordshire and Stoke-on-Trent ICB	6034	6162	2%	5067	82.2%
NHS Birmingham and Solihull ICB	10108	10829	7%	8695	80.3%
NHS Lincolnshire ICB	4462	4627	4%	3692	79.8%
NHS Black Country ICB	6569	7102	8%	5621	79.1%
NHS Shropshire, Telford and Wrekin ICB	2549	2684	5%	2094	78.0%
NHS Coventry and Warwickshire ICB	4410	4812	9%	3716	77.2%
NHS Nottingham and Nottinghamshire ICB	6821	7082	4%	5468	77.2%
NHS Northamptonshire ICB	3799	4064	7%	3098	76.2%
NHS Derby and Derbyshire ICB	6880	7567	10%	4943	65.3%
MIDLANDS	**60746**	**64631**	**6%**	**50395**	**78.0%**

HEALTH ACTION PLAN COMPLETION - MIDLANDS - 2023/2024

ICB or TCP Name	Completed Health Action Plans	% Completed Health Action Plans (LD Register)	% Completed Health Action Plans
NHS Herefordshire and Worcestershire ICB	3638	81.4%	99%
NHS Leicester, Leicestershire and Rutland ICB	4277	81.7%	99%
NHS Birmingham and Solihull ICB	8523	78.7%	98%
NHS Northamptonshire ICB	3029	74.5%	98%
NHS Staffordshire and Stoke-on-Trent ICB	4948	80.3%	98%
NHS Lincolnshire ICB	3588	77.5%	97%
NHS Coventry and Warwickshire ICB	3608	75.0%	97%
NHS Nottingham and Nottinghamshire ICB	5245	74.1%	96%
NHS Black Country ICB	5365	75.5%	95%
NHS Shropshire, Telford and Wrekin ICB	1997	74.4%	95%
NHS Derby and Derbyshire ICB	4671	61.7%	94%
MIDLANDS	**48889**	**75.9%**	**97%**

ANNUAL HEALTH CHECKS COMPLETION - ENGLAND 2023/2024

Region	LD Register 22/23	LD Register 23/24	LD Register Increase %	Completed Health Checks	% Completed Health Checks
London	41014	44030	7%	36521	82.9%
North West	40392	42082	4%	32965	78.3%
North East and Yorkshire	54760	58303	6%	45605	78.2%
Midlands	60746	64631	6%	50395	78.0%
South East	45981	48542	5%	37310	76.9%
South West	32750	34400	5%	25387	73.8%
East of England	34927	37007	6%	26962	72.9%
ENGLAND	**310570**	**328995**	**6%**	**255145**	**77.6%**

HEALTH ACTION PLAN COMPLETION - ENGLAND - 2023/2024

Region	Completed Health Action Plans	% Completed Health Action Plans (LD Register)	% Completed Health Action Plans
North West	32104	75.7%	97%
London	35560	80.7%	97%
Midlands	48889	75.9%	97%
South West	24592	71.5%	97%
South East	35980	75.6%	96%
North East and Yorkshire	43915	75.3%	96%
East of England	25807	69.2%	96%
ENGLAND	**246847**	**74.7%**	**97%**

Data Source - NHS Digital, Learning Disabilities Health Check Scheme ,GP Extraction Service (GPES) via Calculating Quality Reporting System (CQRS) April 2023 - March 2024, Published - 9 May 2024