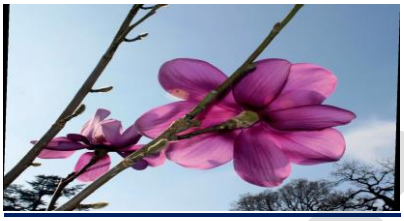
NHS
Brent
Clinical Commissioning Group

Learning Disabilities (LD) Mortality Review (LeDeR) programme

Brent report from 1st October 2017 to March 2019



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Executive Summary

The Learning Disabilities Mortality Review (LeDeR) programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives. It was implemented at the time of considerable spotlight on the deaths of patients in the NHS, and the introduction of the national learning from deaths framework in England in 2017. The programme is led by the University of Bristol and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

All deaths received an initial review; those where there are any areas of concern in relation to the care of the person who has died, or if it is felt that further learning could be gained, receive a full multi-agency review of the death.

From **1st October 2017 to March 2019**, Local Area Contact (Brent CCG) was notified of 22 deaths. The most frequent role of those notifying a death was learning disability professionals, Care Home, Local authority and NHS hospitals.

Key information about the people with learning disabilities whose deaths were notified:

- Over half (73%) of the deaths were of males and (27%) were females.
- Placing Authority: 82% were Brent residents and (18%) in an out-of-area placement.
- They were (100%) single.
- (63.6%) were White British, and (36.3%) were Asians, and Black Africans /Caribbean background.
- Almost half were in their 50s. The youngest age was 25 and highest age- 84 years.
- Majority of the deaths occurred in hospital. This is followed by usual place of resident. With the lowest in Residential Nursing Care and other places.
- The people with Mild learning disabilities (46%)
- Severe learning disabilities (27%)
- Moderate learning disabilities (18%)
- Profound / multiple learning disabilities with (9%)

Review outcomes:
Of the 22 cases reviewed, 73% were identified as good care, but fell short of current best practice in only one minor area. Almost 28% fell short of current best practice in more than one significant area, but this was not considered to have had the potential for adverse impact on the person.

One case (joint funded with CCG-(Brent resident placed in Harrow for respite) fell short of 'current best practice' in one or more significant areas. This was not considered to have had the potential for adverse impact on the person, but some learning resulted from the fuller review of their death. Although, the questionable care this man received from the placement was not provided by the council directly. However, both the CCG and the council were directly responsible for ensuring the quality of care delivered by providers acting on its behalf.

Annual health checks are a reasonable adjustment to overcome known health inequalities faced by people with a learning disability. The checks are for people who need more health support and who may, otherwise have health conditions that go undetected. The review revealed that most people with mild LD did not have their annual health checks completed.

1. Introduction: Health inequalities in relation to people with LD

The persistence of health inequalities between different population groups has been receiving renewed attention recently. Focusing on trends in population mortality and life expectancy, Marmot (2017) has reported that not only have improvements in life expectancy at population level stalled, but that inequalities within and between local authorities, and between areas with different deprivation indices have persisted.

The higher mortality rate in England for people with learning disabilities is both an outcome of health inequalities, and a health inequality itself. An overview of key reports relating to mortality of people with learning disabilities was presented in LeDeR 2015-2016 annual report (http://www. bristol.ac.uk/sps/leder/resources/annual-reports/).

It is more than 10 years since Mencap published Death by Indifference (2007) highlighting 'institutional discrimination' leading to the deaths of six people with learning disabilities whilst in the care of the NHS. Over the past few years, statistical evidence about inequalities in mortality of people with learning disabilities has been accumulating. The Care Act 2014 requires that: People have the right information and advice so they understand what support they can get and how to get it; People's wellbeing is promoted with focus on prevention and health promotion; We work together with partner organisations to improve people's health and wellbeing and we work with the individual and their circle of support to create a plan which meets their needs where assessment determines eligible care and support needs.

The second Annual Report from the Learning Disabilities Mortality Review was published in May 2018. The Government provided its response in September 2018, accepting the review's recommendations and committing to several actions, including a public consultation on mandatory learning disability training for relevant staff by March 2019.

The persistence of health inequalities between different population groups has been well documented, including the inequalities faced by people with learning disabilities. Today, people with learning disabilities die, on average, 15-20 years sooner than people in the general population, with some of those deaths identified as being potentially amenable to good quality healthcare.

2. The LeDeR programme

The LeDeR programme is delivered by the University of Bristol, and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. The overall aims of the LeDeR programme are to support improvements in the quality of health and social care service delivery for people with learning disabilities and to help reduce premature mortality and health inequalities.

A key part of the LeDeR programme is to support local areas in England to review the deaths of people with learning disabilities aged four years and over. The programme has developed and rolled out a review process for the deaths of people with learning disabilities. The LeDeR programme also collate and shares anonymised information about the deaths of people with learning disabilities nationally, so that common themes, learning points and recommendations can be identified and taken forward into policy and practice improvements.

2.1 Core principles and values of the programme

- LeDeR value the on-going contribution of people with learning disabilities and their families to all aspects of our work.
- LeDeR takes a holistic perspective looking at the circumstances leading to deaths of people with learning disabilities and don't prioritise any one source of information over any other
- LeDeR aim to ensure that reviews of deaths lead to reflective learning which will result in improved health and social care service delivery.
- LeDeR aim is to embed reviews of deaths of people with learning disabilities into local structures to ensure their continuation.

2.2 LeDeR methodology

The LeDeR methodology is described in a flowchart in Appendix A and on the LeDeR website at www.bristol.ac.uk/sps/ leder/

3. Brent and Harrow Joint Steering Group

Brent and Harrow steering group have representatives from the NHS Trust, LA, CCGs, Public Health, Service user, Carers/ families and Advocacy organisation. The role of the Steering Group is to take a strategic level oversight of the reviews of deaths of people with learning disabilities, driving transformation to improve care. Meetings are held every 6-8 weeks.

The role includes the following:

- To oversee local reviewers and to deliver the requirements
- To support the identification and sharing of best practice in the review process
- View reports of completed reviews
- Monitor actions and outcome
- Demonstrate impact of changes

4. London borough of Brent

NHS Brent CCG annual report 2017/18 states, there are 369,166 people registered with Brent GPs. London borough of Brent is the most densely populated outer London borough. The population is younger than in England generally but, at the same time, the number of people who are aged 65 and above is expected to grow at a faster pace than the wider population. Between 2011 and 2021, the population aged between 65 and 74 is expected to grow by 16%. The number of 75 to 84 year olds will increase by 16% and those over 85 will increase by 72%. Within this period, the total population is projected to grow at a rate of 7%.

Brent is the most diverse borough in the country, with 65% of its residents classifying themselves as Black, Asian and minority ethnic (BAME) – most of whom are either of Black or Indian descent. Over 130 languages are spoken in schools in Brent. Between 2014 and 2030, the number of adults aged 18 to 64 with a learning disability is predicted to rise by 8%. Furthermore, the number of adults aged 65 and over in Brent predicted to have a learning disability is projected to increase by 52% between 2014 and 2030.

In Brent, approximately 3,300 adults are registered as diagnosed with a learning disability with Brent Clinical Commissioning Group (CCG). 1912 are known to Brent Council with approximately 640 in receipt of statutory funded services to meet their Care Act eligible needs.

Public Health data indicates that the prevalence of adults with learning disabilities aged 18-64 is predicted to increase by 8% over the next 15 years and the prevalence of adults with learning disabilities aged 65+ is expected to increase by 52%. We know that this is a growing population with varied and often complex needs.

5. LeDeR Key Performance Indicators (KPI)

NHS England introduced KPIs which require the below targets to be achieved by the end of Sept 2018:

- % unassigned reviews: 10%
- % completed reviews: 50%
- % reviews in progress: 90%

6. Staffing

Staffing one part time staff with expertise in LD patients was commissioned in September 2018 to clear the backlog of reviews in Brent. The post holder completed reviews for the London boroughs of Brent and Harrow. This project ended in March 2019. These suggest that the local NHS providers including the local authority to train their staff to undertake reviews going forward.

7. Death Notifications in Brent

From **1st October 2017 to March 2019**, **22** deaths were notified to the Brent Local Area Contact (LAC). The most frequent role of those notifying a death was learning disability professionals, care home, Local Authority and NHS hospitals.

8. Challenges in allocating reviews

It is to be expected that a programme of this size and complexity, requiring the input and support from a range of stakeholders, would face challenges to its delivery. The most significant challenge has been the timeliness with which mortality reviews have been completed, largely driven by these.

Key factors below:

Challenges in allocating reviews 2017/18	Action plans
The low proportion of people trained in LeDeR methodology that has gone on to complete mortality reviews. Trained reviewers having insufficient time away from their other duties to be able to complete LeDeR review. Delays in accessing medical notes: some medical notes have been archived therefore create delays in obtaining notes in a timely manner.	Issues were escalated to senior manages in various organisations to obtain assurances. The message was (Deaths of LD patient should not be archived until LeDeR review was completed). Staffs were encouraged to undertake online training with support from Local Area Contact (LAC). LACs ensured managers are involved / informed during LeDeR allocations, to ensure staffs was supported and reviews are counted within job roles / duties.

9. Notification of death

9.1 Number of death notifications until March 2019

Deaths notifications	Completed reviews	On-going reviews
22	22	0

9.2 Death notifications from April 2019

Deaths notifications	Completed reviews	On-going reviews
0	0	0

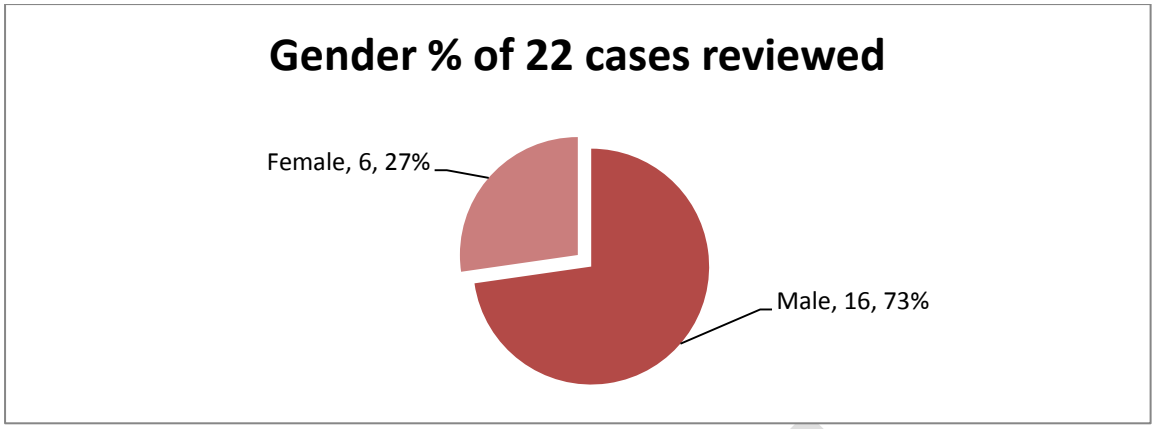
9.3 Reviewers Organisation

NHS Brent CCG	12
Brent Local Authority	0
CNWL	1
LNWH	0
Independent Reviewer	9

10. Demographic characteristics and information about the deaths of people with learning disabilities

10.1 Gender

Key information about the gender of Brent patients with learning disabilities whose deaths were notified are:

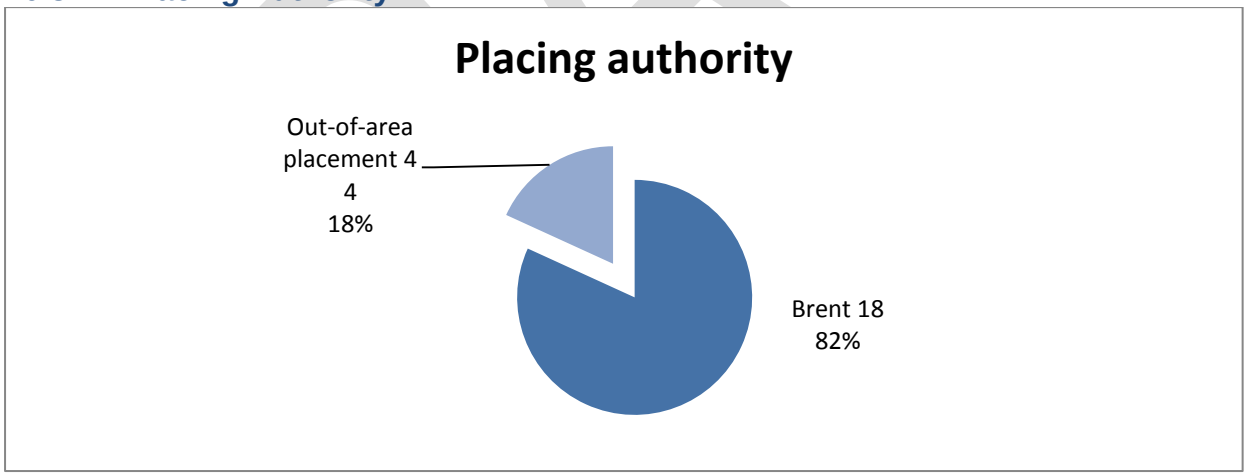


10.2 Marital status

Of the 22 cases reviewed, (100%) were single. This is slightly higher that the data reported Nationally in the 2017 LeDeR Annual Report, 96% of people who died were single (96%). The national data showed that women were more likely to have been married, divorced, widowed or separated than were men (6% of women, compared to 2% of men).

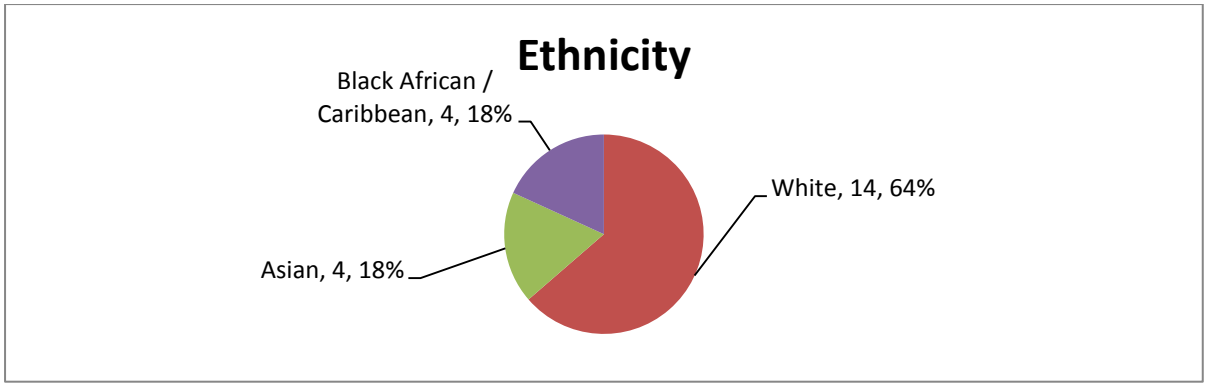
The data on Brent suggests that, compared to the general population, the population of people with learning disabilities may have less access to support through their social network. It is not possible to comment meaningfully on how Brent compares to the national LeDeR data based on the current small sample size.

10.3 Placing Authority



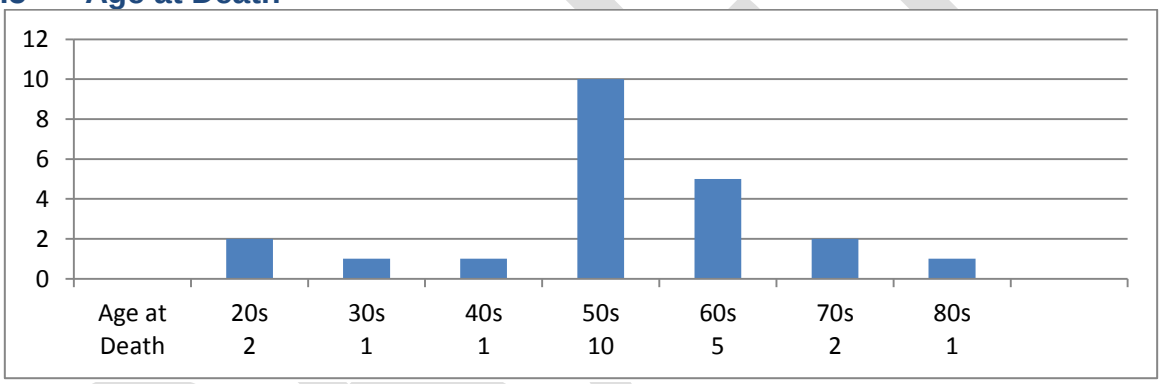
10.4 Race/Ethnicity

Brent is ethnically diverse: 64.7% of the population is Black, Asian or other minority ethnicity (BAME). The Indian ethnic group currently makes up the largest minority group representing 17.6% of the population, followed by Other Asian (12%). The White ethnic group represents 33%.



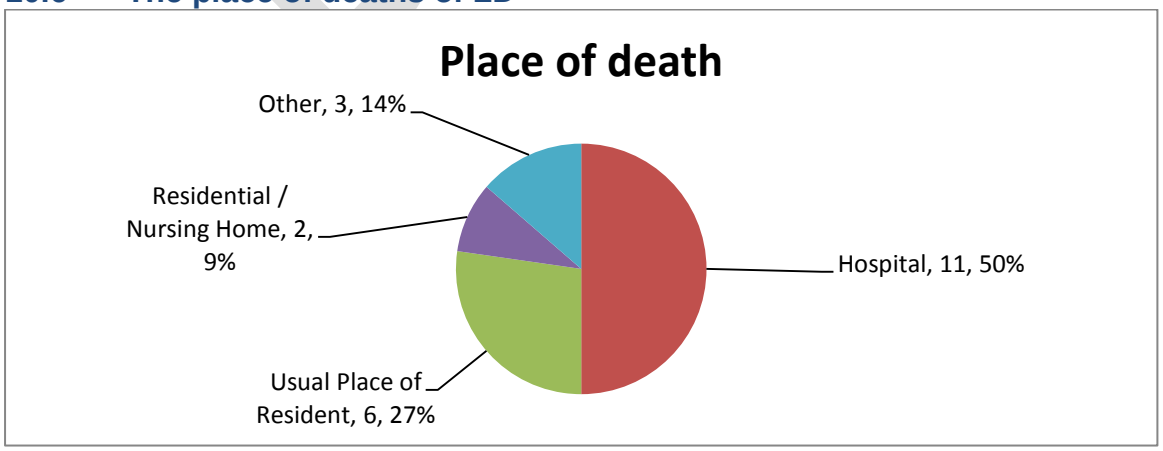
Ethnicity in Cases: 14 -White British, 4- Asians and 4 –Black Africans /Caribbean**.** Compared to 2017 annual report, the person's ethnic background was reported for 1,145 deaths notified. Almost all of these (93%) were from a White ethnic background, 4% were from an Asian background, and 4% were from other backgrounds. The proportion of people whose ethnic group was described as 'White' was higher than the 86% recorded for England and Wales as a whole (ONS, 2011).

10.5 Age at Death



The youngest age is 25 and the highest age is 84 years. The average age at death for people with mild learning disabilities was still considerably less than that of people in the general population. There are a huge number of deaths in their fifties. This may be a combination of many factors.

10.6 The place of deaths of LD



In England in 2016, 47% of deaths of the general population occurred in hospital (National End of Life Intelligence Network, 2017). Table above shows the place of death, as can be seen; the proportion of people with learning disabilities who died in hospital (11 out of 22) was greater than that of the general population.

10.7 Severity of LD

In Brent, approximately 3,300 adults are registered as diagnosed with a learning disability with Brent Clinical Commissioning Group (CCG). 1912 are known to Brent Council with approximately 640 in receipt of statutory funded services to meet their Care Act eligible needs.

10.8 Brent LA data

Severe/ profound	457
Moderate	553
Mild LD	738
191 adults with autism are also known to Adult Social Care	133 also have a learning disability

10.9 Severity of LD in LeDeR cases

Profound / Multiple	2 (9%)
Severe Learning Disabilities	6 (27%)
Moderate Learning Disabilities	4 (18%)
Mild Learning Disabilities	10 (46%)

The box indicated that people with Mild Learning Disabilities (LD) is higher as compared with the other LD types. Evidence from the review demonstrated that people with mild LD tends to live independently with minimal support provided. This includes the provision of a Hospital Passport, lack of LD Action plan and Social Care reviews. They are also irregular in attending appointments, fluctuating mental capacity, lack of representatives at assessments, and issues regarding medications compliance.

11. Living Environment

Nursing Home	9
Supported Living	5
Independent flat	4
Residential home	3
Family Home	1

12. Causes of Deaths of LD

Case 1-Pneumonia	Case 2-Epileptic seizure	Case 3-Epileptic seizure

Case 4-Cardiac pulmonary Degenerative disease	Case 5-Cardiomegaly and Obesity	Case 6-Bronchopneumonia Congestive Heart failure.
Case7- Myocardial infarction	Case 8-Apiration Pneumonia	Case 9- Hospital acquired Pneumonia
Case 10-Chest Sepsis	Case 11-Pulmonary embolism	Case 12-Phenylketonuria
Case 13- Left Partial Anterior Circulation Infarct (Spontaneous)	Case 14- Myocardial Infarction	Case15- Cardiac respiratory Arrest
Case 16-Chronic kidney disease	Case 17- Hypoxic Brain Injury secondary to out of hospital cardiac arrest	Case 18- Hyperkalaemia Hepatorenal syndrome. Liver cirrhosis
Case 19- Bilateral aspiration pneumonia	Case 20-Aspiration pneumonia. Unsafe swallow	Case 21-Cardiac arrest.

Case 22- 1a -Cardiorespiratory arrest 1b- Prader Willi syndrome

Health: Data from NHS Digital shows that, on average, women with a learning disability have around an 18 year shorter life expectancy than the general population, and males around 14 years. People with learning disabilities are **26 times more likely to have epilepsy**, **eight times more likely to have severe mental illness and five times more likely to have dementia.** They are also **three times more likely to suffer with hypothyroidism and almost twice as likely to suffer diabetes, heart failure, chronic kidney disease or stroke.**

1 in 2 eligible women with a learning disability received breast cancer screening compared to 2 in 3 eligible women without a learning disability. **Obesity is twice as common in people aged 18-35 with learning disabilities. Being underweight is twice as common in people aged over 64 with learning disabilities,** compared with patients with no learning disability. These statistics highlight the need for regular health screening and health promotion for this group.

Annual health checks are a reasonable adjustment to overcome known health inequalities faced by people with a learning disability. The Annual Health Checks are for adults and young people with learning disabilities who need more health support and who may otherwise have health conditions that go undetected. The review uncovered that most people with mild LD did not have their annual health checks completed or the provision of a Hospital passport.

13. Completed review of deaths of people with LD (Good Practice)

Good practice areas from reviewed cases. This was the common themes across all reviews.

- Personalised care plan in support to achieve patient's goals
- Good support plan and Health Passport
- Evidence of information sharing among all professionals
- Implementation of reasonable adjustments where applicable
- Completion of Annual Health Checks and regular medical reviews (severe / moderate LD)

Case study

Sample of case 1. *XX was diagnosed with Severe LD and also severe scoliosis and cerebral palsy which affect her posture. XX lived at the same Nursing Home since October 1995, she was 72 years old. XX was a wheelchair user and required support with all aspects of daily living including support with personal care. She was an affectionate individual; she had clear likes and dislikes. Enjoyed playing with balloons, listening to music, shopping, cinema trips and visiting local parks.*

COMMUNICATION: XX was non-verbal and does not use any known or formed communication system or aids. She can communicate her basic wishes and moods by using idiosyncratic sounds, gestures, eye pointing and facial expressions. Staff at the Care Home received Intensive Interaction and sensory stimulation skills training and XX attended some of the workshops with staff that she seemed to have enjoyed and has become more relaxed with the interaction sequences and exchanges of behaviour. XX died in hospital from Aspiration pneumonia.

Review: XX was referred to specialist services as required. Home visits by GP. Annual Health checks completed. The review was marked as 'good' but fell short of current best practice in only one area. Care Home application for deprivation of liberty safeguards (DoL)s was not authorised by the Supervisory Body (Out-of- area placement).

14. Overall assessment of reviews

Blue- excellent, Green-good, Grey-satisfactory, Orange -fell short on some areas, Yellow fell short on more areas and Red- fell short of current best practice.

	LeDeR category	n	%
1	This was excellent care and met current best practice	0	0%
2	This was good care, which fell short of current best practice in only one minor area	16	73 %
3	This was satisfactory care, falling short of current best practice in two or more minor areas, but no significant learning would result from a fuller review of the death	4	18%
4	Care fell short of current best practice in one or more significant areas, but this is not considered to have had the potential for adverse impact on the person and no significant learning could result from a fuller review of the death	1	4 %
5	Care fell short of current best practice in one or more significant areas, although this is not considered to have had the potential for adverse impact on the person, some learning could result from a fuller review of the death	1	4%
6	Care fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person	0	0%

15. Recommendations and learning points

Brent Safeguarding Adults Board to:

- note the outcomes of the learning disability mortality reviews in Brent; and
- support the LeDeR steering group develop an action plan to address the areas of learning listed below.

15.1 Care package reviews need to be done if a person's needs change significantly, to ensure the right level of support is offered at all times, and all areas of needs are addressed. This recommendation helps to ensure people's care needs are not neglected.

15.2 Annual Health Checks need to be done by a GP for the majority of adults with a learning disability. NHS England has set a target in 2019/20 for Brent to deliver 1,446 annual health checks for the population of 1,659 adults on the GP learning disability register. This would help the early diagnose of physical illness, and early referral to health services. This recommendation helps address and inequality for health access for a group of vulnerable adults.

15.3 Care plans for people with LD need to ensure meaningful involvement of families / carers. This is particularly important where there are concerns about the individual's mental capacity to consent to the proposed care plan. The carer's needs should be considered through a carer assessment under the Care Act 2014.

15.4 Professionals need a better understanding of how to use the Mental Capacity Act 2005 (MCA) when planning and delivering care for a person with a learning disability. This includes the application and authorization of Deprivation of Liberty Safeguards (DoLS). This links to the Safeguarding Adults Board priority to Make Safeguarding Personal.

15.5 Professionals should be able to explain the benefits of a Hospital Passport for people with a mild learning disability. This would help them have better access to services than can reduce their risk of ill health, and risk of mortality. This recommendation helps address and inequality for health access for a group of vulnerable adults.

16. Conclusion

Of the 22 cases reviewed, 73% were identified as 'good care', but fell short of 'current best practice' in only one minor area. Almost 28% fell short of 'current best practice' in one or more significant areas, but this was not considered to have had the potential for adverse impact on the person.

One case (Brent resident placed in Harrow for respite) fell short of 'current best practice' in one or more significant areas. This was not considered to have had the potential for adverse impact on the person, but some learning resulted from the fuller review of their death.

The Deprivation of Liberty Safeguards (DoLS) and The Mental Capacity Act 2005 (and the Code of Practice 2007) describes the steps a person should take when dealing with

someone who may lack capacity to make decisions for themselves. It describes when to assess a person's capacity to make a decision, how to do this, and how to make a decision on behalf of somebody who cannot do so themselves. Applying the process properly would sometimes not change the outcome for most of the people affected, other than confirming that it is in their best interests to be deprived of liberty. However, it is possible that some of the people stuck in the backlog for years should never have been deprived of their liberty.

People with a learning disability often have poorer physical and mental health than other people. This does not need to be the case. An annual health check provides holistic views about the person's health and finding any problems early, so they can get the right care. There are gradual changes in the organisation of healthcare for people with learning disability. GPs are expected to provide annual health checks, and learning disability liaison nurses have been employed in acute hospitals.

There are still concerns that the up take in annual health check people with mild LD is low. These groups of people are less likely to be offered appropriate diagnostic investigations or treatments in a timely manner. There are challenges also to facilitate a simple blood test in a person with a learning disability who may be frightened and refusing. People with a learning disability have a legal right for reasonable adjustments to be made so they can get the same benefits from healthcare services as everyone else.

Community learning disability teams can support people with learning disabilities to access mainstream health services. Recommendation four of the LeDeR report 2018 is that "all people with learning disabilities with two or more long-term conditions (related to either physical or mental health) should have a local named health care coordinator." Community learning disability nurses are ideally placed to do this work.

Case study

AA had a diagnosis of Mild Learning disability, diabetes, high blood pressure, and high cholesterol. She was overweight and used a walking stick on occasions when mobilising. She lived in an independent flat and suffered from anxiety. She would usually call her mother many times per day for assurance. AA would often call the emergency 111 services and was frequent in A&E hospital for various complain, although she was closely monitored by her GP and her consultant psychiatrist. She was also forgetful and needed assurance. On record, she had good insight into her health.

Daughter disclosed: on AA's death, her grandmother noticed AA had not called the whole day. Grandmother sought support, and attended AA's flat. There were no answer, they used a (spare keys). On gaining entrance, they saw AA on her bed 'presumed dead'. The Coroners gave the Cause of Death as '' Cardiomegaly & Obesity''.

Review: There were some reasonable adjustments that were not made available for AA. Going into hospital can be a worrying time for anyone. But it can be particularly worrying and stressful for someone with a learning disability.

- *AA was not provided with a Hospital Passport. This would have enabled all professionals to understand her needs and how to care for her.*
- *Weight issues. There no evidence on record that her weight was addressed. I.e. provision of leaflets etc.*

- *The review noticed AA was unable to cope with changes. There were two major changes in* months leading to her death. She was discharged by her consultant psychiatrist and at the same time, there were changes in the hours of her care packages (reduced). These changes could have been gradually introduced.
- AA did not have an allocated key worker to provide additional support. People with LD may have difficulty expressing themselves of finding the right words. It is vital an advocate or relative / carer are present during assessments to provide emotional *support etc.*

Advice for GPs

NHS England has provided details of a clinical champion to provide advice to GPs. The clinical lead in London is Dr Nicola Payne, London GP Champion for LeDeR Programme, Associate Medical Director, NHS England (London Region). She can be contacted at nicolapayne@nhs.net, or by phone on 07502446173.

Appendix A Reporting the death of a person with LD

LeDeR Process Flowchart

Notify a death

Anyone can notify LeDeR including people with learning disabilities themselves, family members, friends and paid staff.

Online: https://www.bris.ac.uk/sps/leder/notification-system/ OR

Call LeDeR on 0300 777 4774

A poster about how to notify a death is also available here (PDF, 193kB)

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Notifications

LeDeR Team receive notification. Identify those meeting criteria for review.

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Inform and assign cases for review
(Four months from this stage to sign off)

LeDeR Team informs NHS Brent CCG Local Area Contact (LAC) of a new case.
NHS Brent CCG LAC identifies suitable reviewers and informs LeDeR.
LeDeR Team informs reviewer of the case allocation.

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Local reviewer: pre-initial review information gathering

Is this individual subject to any other existing review process.

YES	NO
Link in with other process Establish the nominated contact for the other review process and liaise with them. Where possible collect core data required for the LeDeR review. Provide learning disabilities expertise to other review process if appropriate and required.	**Initial Review** Conversation with someone who knew the person well. Review of relevant case notes. Complete pen portrait, timeline and action plan.
Agree with the other review process Complete initial review. Agree comprehensive pen portrait and timeline. Agree potentially avoidable contributory factors. Identify lessons learned. Agree on good practice and any recommendations.	Decide whether further action is required Further action is required if: Additional learning could come from a fuller review; If it is a Priority Themed Review; If red flags indicate this.
Summary and Close The completed report and action plan is returned to the **Local Area Contact for sign off** and then sent to the LeDeR Programme.	**No Further Action** The completed report and action plan is returned to the **Local Area Contact for sign off** and then sent to the LeDeR Programme

Share with Steering Group

Local Area Contact shares anonymised learning points and actions with their relevant Steering Group to ensure learning is embedded and action plans are taken forward.

Appendix B Why recognizing deterioration earlier is so important

Deterioration in someone's health is when their normal clinical state changes. This change increases that person's risk of morbidity, organ failure, further disability, or maybe even death. Following a number of national inquiries into the death of patients in hospitals, the need for a standardised system to detect earlier a patients' clinical deterioration was highlighted. This led to the Early Warning Score (EWS) system being developed for use in hospitals.

Eileen McNamara et al 2018, wrote in BMJ; preventing avoidable deaths of people with a learning disability: Is LeDeR enough? It has been researched that people with a learning disability die on average 16 years younger than people without a learning disability. It is estimated that 1,200 people with a learning disability die avoidably in the NHS each year. Shocking as these statistics are, we have known about the premature mortality and the significant health inequalities faced by people with a learning disability for over two decades. The charity, Mencap, has been influential in increasing public awareness. Their reports, including Death by Indifference (2007), highlight poor clinical care contributing directly to the deaths of people with a learning disability.

In response to LeDeR reviews, there has been a gradual change in the organisation of healthcare for people with learning disability. GPs are expected to provide annual health checks, learning disability liaison nurses have been employed in acute hospitals, and staff trained in the Mental Capacity Act.
Annual health checks for people with learning disability can significantly improve health outcomes, but uptake remains low. People with learning disability are less likely to be offered appropriate diagnostic investigations or treatments in a timely manner. It remains remarkably difficult to facilitate a simple blood test in a person with a learning disability who is frightened and refusing.
Properly resourced community learning disability teams can support people with learning disabilities to access mainstream health services. Recommendation four of the LeDeR report is that "*all people with learning disabilities with two or more long-term conditions (related to either physical or mental health) should have a local named health care* coordinator." Community learning disability nurses are ideally placed to do this work.

References

- Eileen McNamara, consultant psychiatrist, Barnet Learning Disabilities Service.
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- Mencap. Death by Indifference. 2007.
- Michael J, Richardson A. Healthcare for All: The Independent Inquiry into Access to Healthcare for People with Learning Disabilities. Vol. 13, Tizard Learning Disability Review. 2008. p. 28–34.

Appendix C The 2017-18 LeDeR Annual Report published in May 2018.

The Review recommended that: **Mandatory learning disability awareness training** should be provided to all staff, delivered in conjunction with people with learning disabilities and their families.

Initiatives awareness: there are initiatives in place to raise awareness of the needs of people with learning disabilities, and improve the delivery of health and care services. Some of these are:

- NHS Improvement is developing Improvement Standards for Learning Disability. The four key standards relate to improving the workforce, improving the provision of reasonable adjustments, improving specialist learning disability NHS services, and improving inclusion and engagement with people using services and their family carers.
- NHS Digital is developing a nationally available flag to be placed on a person's Summary Care Record that will indicate if the person has been identified by a care provider as being potentially eligible for reasonable adjustments, and what reasonable adjustments in care should be considered.
- The NHS England Transforming Care programme is working to improve health and care services so that people with learning disabilities can live in the community, with the right support, close to home.
- The Royal College of General Practitioners has developed a toolkit to help GPs and practice nurses carry out learning disability annual health checks to a high standard.
- NHS England is developing practice guidance for supporting people with learning disabilities who have poor outcomes in some long-term conditions, including diabetes, epilepsy, heart disease and dysphagia. The diabetes guidance is now available at
  https://www.england.nhs.uk/rightcare/products/pathways/diabetespathway

Appendix D LeDeR methodology

Notification of a death

The person reporting the death is asked to provide relevant core information. The information provided is checked by the LeDeR team to ensure that the death meets the inclusion criteria for the LeDeR programme. Once confirmed, the death is allocated to a reviewer under the guidance of the Local Area Contact.

Initial review

An initial review is completed for all deaths of people with learning disabilities that meet the inclusion criteria. The purpose of the initial review is to provide sufficient information to determine if there are any areas of concern in relation to the care of the person who has died, or if any further learning could be gained from a multi-agency review of the death that would contribute to improving practice.

Multi-agency Review of a death

A multi-agency review of a death involves the range of agencies that had been supporting the individual who had died. It considers:

- Any good practice that has been identified in relation to the person's death
- Any potentially avoidable contributory factors to the death.
- If there were any aspects of care and support that may have changed the outcome, had they been identified and addressed.
- If there have been any lessons learned, as a result of the review of the death.
- If there should be any changes made to local practices, as a result of the findings of the review.
- If there are any wider recommendations that should be made.

Action planning process

At the end of the initial and multi-agency review forms there is space for reviewers to identify learning and recommendations (from initial reviews) and action points (from multi-agency reviews). Copies of completed reports are sent to the local LeDeR Steering Group, which agrees relevant actions, and oversees their implementation in conjunction with relevant partners and health and social care agencies in their area.

The LeDeR quality assurance process

The Quality Assurance process involves a small panel of LeDeR team members looking at recently submitted reviews, to work to ensure national consistency in the quality of mortality reviews. Quality assurance enables the LeDeR team to give constructive feedback to reviewers to enrich their future reviews. It also gives the LeDeR team invaluable insight into training needs: themes picked up in quality assurance are incorporated into training improvements on an on-going basis.

The Report draws on a number of sources including: NHS Digital, LeDeR 2017/18 Annual Report and Brent CCG Annual Report and Brent CCG Patient and Public Engagement Report 2018.