NHS
Bury
Clinical Commissioning Group

Learning Disability Mortality Review[1] (LeDeR) programme Annual Report

April 2020 – March 2021

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[1] The name of the LeDeR programme is changing to '**Learning from lives and deaths – People with a learning disability and autistic people (LeDeR)'.**

Learning Disability Mortality Review (LeDeR) programme
Annual Report - 2020/2021

1. Introduction

1.1. This is the second annual report of the Learning Disability Mortality Review (LeDeR) programme being delivered by NHS Bury Clinical Commissioning Group (CCG).

1.2. It presents information about the LeDeR programme and its findings to date regarding the deaths of people who have a learning disability aged 4 years and over that have been notified to the programme. This includes both national and Bury specific data, summarising the quality of health care received. Positive practice and areas for improvement are detailed, with recommended actions to implement this learning.

1.3. This report covers reviews of Bury residents with a learning disability completed between 1st April 2020 and 31st March 2021.

2. Background

2.1. The LeDeR programme was established by NHS England (NHSE) in 2016 to improve the standard and quality of care for people with a learning disability[2].

2.2. The programme introduced a new review process for deaths of people with a learning disability aged 4 years and over. All deaths, regardless of where they took place and whether expected or not, are required to be locally reviewed.

2.3. The drivers for the LeDeR programme were, and still are, the persistence of health inequalities between the general population and people with a learning disability. People with a learning disability are three times more likely to die early from causes that could have been avoided with access to good quality healthcare; deaths occur on average, 15-20 years sooner than the rest of the population. The need to act to address this disparity was a key recommendation of the Confidential Inquiry into Premature Deaths of people with a Learning Disability (CIPOLD)[3]. The LeDeR programme aims to reduce health inequalities and avoidable deaths by informing public policy through a better understanding of the care provided and the causes of death.

2.4. The University of Bristol ran the LeDeR programme funded by NHSE until 31st May 2021. The university held the national LeDeR database and received all death notifications, allocating them out to local areas for review. To prompt local and national system-wide change, the university produced learning briefs and an annual national report to government. Since the 1st June 2021, NHSE has taken over responsibility for running the programme and the university has stood down from its role.

2.5. The LeDeR programme is part of a wider national Learning from Deaths Framework[4],

[2] The definition of learning disability used by the LeDeR programme is from the 'Valuing People - A New Strategy for Learning Disability for the 21st Century' (2001) report and includes the presence of *'A significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which started before adulthood, with a lasting effect on development.'*
[3] CIPOLD (2013) was itself a key recommendation of Mencap's 'Death by Indifference' report; its purpose to review if the learning from premature and preventable deaths of people with a learning disability was being implemented.
[4] National Guidance on Learning from Deaths 2017, 2019 (National Quality Board).

bringing greater scrutiny of deaths and standardisation of mortality review processes. Acute, mental health, community and ambulance trusts are all now required to improve how they learn from the deaths of patients, including how they engage with bereaved families. The new Medical Examiner system is bringing a further layer of independent scrutiny, confirming cause of death for non-coronial deaths.

2.6. The Learning from Deaths framework and the LeDeR programme are interlinked, with both gaining momentum since their inception.

2.7. CCGs are responsible for the completion of mortality reviews and the collation of subsequent learning, developing and delivering strategic and operational improvements[5]. Health and social care commissioners and providers are required to work together, in partnership with families of the deceased and with people with a learning disability, to identify and act on learning from reviews.

2.8. The deaths of children (aged under 18) with a learning disability are reviewed by the statutory Child Death Review programme, and do not have a LeDeR review. Any learning identified is fed back to the relevant CCG and to the national LeDeR team.

2.9. The CCG's Quality Team is responsible for the LeDeR programme in Bury. This is done in conjunction with the Local Authority and health and social care providers across the health economy. The programme in Bury has been in place since February 2017.

2.10. To take forward the learning opportunities presented by LeDeR a multi-agency Learning Disabilities Practitioner Forum was established in April 2021 and will assist with ensuring GP practices and providers receive targeted support when undertaking reviews and embedding quality improvements in service provision.

2.11. The CCG employs one reviewer on a part-time basis. A quality assurance process ensures each review is checked regarding identified learning and the recommendations made before submission to the national LeDeR team.

3. Challenges

3.1. The LeDeR programme has continued both nationally and locally during the COVID-19 pandemic despite very significant pressures on services and a national backlog of death reviews requiring completion from previous years.

3.2. Consistent with the Greater Manchester, regional and national picture, at the end of March 2020 Bury had a backlog of 8 reviews. These were passed over to a national team hosted by the North East Commissioning Support (NECS) unit.

3.3. To embed and drive the LeDeR programme the NHS Planning Guidance includes requirements for CCGs and for NHS Trusts regarding mortality reviews.

3.4. Trusts must comply with the National Guidance on Learning from Deaths, which requires their mortality processes to be compliant with the LeDeR programme.

[5] From 1st April 2022, under a new national LeDeR Policy and reflecting new arrangements in the NHS, responsibility to deliver the LeDeR programme will move from CCGs to local integrated care systems (ICSs).

3.5. Learning disability improvement standards were also introduced, requiring Trusts to monitor and review the quality of care they provide to people with a learning disability.

3.6. Bury CCG is compliant with the NHS Planning Guidance, with a local LeDeR (Transforming Care) group in place and an identified Executive Lead. Reviews are being undertaken in a timely manner, with a system to collate and act on local and national learning.

3.7. LeDeR reports are provided to the CCG's Quality and Performance Committee and the CCG's Governing Body, plus the Strategic Partnership Board (which is jointly run with Bury Local Authority).

4. Underreporting

4.1. There is no accurate record of the total number of people with learning disabilities in England, nor of the number of deaths each year.

4.2. Estimates from Public Health England suggest the approximate number of deaths of people with learning disabilities of all ages each year to be more than 3,400.

4.3. The number of death notifications to the LeDeR programme has increased over time, both nationally and locally, as the programme has become more established. To date, at 31st March 2021, Bury CCG has received 43 notifications about a Bury resident with a learning disability who has died.

Notifications received by Bury CCG					Total
2017	2018	2019	2020	2021 to 31/03/21	
3	15	11	10	4	43

4.4. The impact of Covid-19 has been significant, shortening the lives of many. Nationally during 2020, 24% of deaths notified to LeDeR were from Covid-19 (whilst the death rate in the general population from Covid-19 was 13%).

5. Number and status of Bury's LeDeR reviews

5.1. Thirty-nine of Bury's 43 reviews have been completed, with the remaining 4 open and in time (at 31st March 2021).

5.2. Eighteen reviews were completed in 2020/21 (including the 8 backlog reviews).

5.3. Confidence in interpreting local findings and understanding the experiences of Bury residents with a learning disability and how these compare across Greater Manchester and England, and to those of the general population has increased. The 2019/20 annual report reported 58% of Bury's reviews had been completed. To date (at 31st March 2021), 90% of Bury's reviews are now complete.

6. Findings of the 18 LeDeR reviews for Bury residents completed in 2020/21

6.1. Demographic information

Age range	21 to 72 years (average 53 years)	
Gender	Male	12
	Female	6
Ethnicity	White British	15
	Dual black/white heritage	1
	South East Asian heritage	2
Place of death	Hospital	14
	Home	4
Level of learning disability	Profound/multiple	4
	Severe	2
	Moderate	5
	Mild	7

6.2. Cause of death

Cause of death	Number	Additional cause noted
Pneumonia	5	Yes – septicemia x 2
Covid-19[6]	3	Yes
Cancer	3	No
Aspiration Pneumonia	2	Yes
Cardiac arrhythmia	2	Yes
Chronic lung disease	1	No
Pulmonary embolism	1	Yes
Status epilepticus	1	Yes

6.3. Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR)[7]

Eleven DNACPR orders were in place. These had been completed and carried out appropriately[8].

6.4. Annual Health Checks[9]

[6] In 2020, the leading cause of death nationally in people with a learning disability was Covid-19.

[7] Cardio-pulmonary resuscitation (CPR) is the chest compressions and artificial breaths given when a person's heart has stopped. A decision not to attempt, a DNACPR order, is made and recorded in advance when it is not in the best interests of the person. Decisions about DNACPR must not be based on assumptions related to the person's age, disability, or the professional's subjective view of the person's quality of life.

[8] National LeDeR data show a small proportion of DNACPR decisions are not made correctly (4% in 2018, 4% in 2019, 6% in 2020).

[9] As people with a learning disability often have poorer physical and mental health than the general population, General Practice provide an annual health check for adults and young people aged 14 or over with a learning disability.

Sixteen people had received regular annual health checks at their General Practice.

6.5. Quality of care provided

6.5.1. An overall assessment of the quality of care received is made at the end of a LeDeR review - whether it exceeded or met expected good practice or whether it fell short.

Quality of care provided		
Excellent	3	2 included cancer care
Good	8	
Satisfactory	1	
Below standard	6 For 5 people care fell short, impacting on their wellbeing but did not contribute to their death. For 1 person their care fell short and significantly impacted on their wellbeing and may have contributed to their death.	1 required a multi-agency LeDeR review (MAR)

6.5.2. Of the 18 Bury reviews completed in 2020/21, there were substantial examples of skilled and person-centred care, of complex needs being met and of effective collaboration between providers.

6.5.3. Of the 7 reviews where elements of care were not good, recommendations were made to prevent this happening again. The changes required to put this learning into action are generally needed across services - they need to be both joined-up and consistent across all the services that a person with a learning disability living in Bury may use. System leaders are required to make this happen.[10]

7. Action from Learning

7.1. Summary of local learning in Bury

7.1.1. Four ongoing themes are evident:

a. Reasonable Adjustments not being provided
b. Poor communication with the person and between services
c. Lack of confidence and competence in applying the Mental Capacity Act 2005
d. Avoidable respiratory conditions remaining the most frequent cause of death

7.1.2. As seen across the rest of England, Reasonable Adjustments are still not always understood, asked about, recorded, or provided consistently in Bury's General Practices and in local hospitals.

7.1.3. One Reasonable Adjustment that has a significant positive impact in General practice is seeing the same clinician, particularly when the person with a learning disability is

[10] Under the new national LeDeR Policy, from April 2022, there will be a much stronger emphasis on the delivery of actions that come out of reviews and the holding of local systems to account for the delivery of these.

unwell. An ongoing lack of consistency and continuity hinders relationship building. This limits a GP's ability to understand and meet the specialist needs of the person. This is noted even when the person has a named GP and when the practice knows the person has a learning disability. In hospital, for both inpatient and outpatient appointments, information about Reasonable Adjustments is not always shared between departments and wards.

7.1.3. With regard to communication, local systems and processes do not always support the sharing of key information about a person's learning disability diagnosis and the Reasonable Adjustments they need. This is the case both within General Practices and hospitals and between General Practices and hospitals. Both still send written communication (texts and letters), to people who cannot read or write, even when it is known verbal communication is needed or preferred. Information about carers/advocates/supporters is also not always recorded accurately or missed.

7.1.4 There is an increased need for discussion and consultation with safeguarding colleagues about staff in Bury's General Practices understanding and applying the Mental Capacity Act 2005 regarding supported decision making and the best interest process.

7.1.5 The impact of the Covid-19 pandemic raised potential Deprivation of Liberty Safeguards (DOLS) due to risks presented by people with a learning disability usually able to go out independently when they did not understand and/or adhere to Covid-19 safety measures and the resultant risks posed to housemates and staff. Changes in support systems were made to provide the least restrictive option and, where needed, funding increased to finance more staff support.

7.1.6. There were also rebound implications on behaviour and mental health from restricting people's lifestyles when they did not understand why this occurred and/or struggled with significant changes to their routine.

7.1.7 Respiratory conditions (bacterial pneumonias and aspiration pneumonia) remain the most frequently reported cause of premature mortality, both nationally and locally.

7.2 <u>Actions taken in Bury</u>

As a result of the multi-agency LeDeR review and wider review learning, several changes to systems have been made or are in progress:

- Additional provision of PPE[11] for staff

- Pulse oximeters[12] for people with a learning disability supported by statutory funded services and the voluntary sector

-Social work reviewers have changed their assessment format to include MCA considerations covering all decision-making abilities to ensure families as well as service providers understand issues around capacity

[11] Personal protective equipment (PPE) is protective clothing, helmets, goggles, or other garments or equipment designed to protect the wearer's body from injury or infection

[12] A pulse oximeter is a small clip-like device that attaches to a finger (or toe or earlobe) to painlessly measure a person's blood oxygen levels, which can drop without the person feeling poorly.

- Additional training for General Practices is being offered regarding Reasonable Adjustments and capacity and decision making

- Computer systems are being modified to flag up Reasonable Adjustments each time a person with a learning disability visits their General Practice

- Extension to the CCG's Transforming Care Group's terms of reference to discuss anonymised reviews

- A new multi-agency forum has been created, with the resulting improvement programmes of work directly reflecting local and national learning, these are:

    - Improving communication between all health and social care teams
    - Making Reasonable Adjustments in General Practice to improve relationships
    - Improving understanding of the Mental Capacity Act
    - Improving understanding by health and care staff of the physical illnesses that greater affect people with a learning disability e.g. pneumonia, sepsis, constipation, dysphagia (difficulty swallowing), Covid-19

7.3 Evaluating impact

Key actions are now included in the terms of reference for the multi-agency LD Practitioner Forum.

8 Recommendations identified in the Independent Review into Thomas Oliver McGowan's LeDeR review process

8.1 In October 2020, an independent review into the LeDeR process relating to the death of Thomas Oliver McGowan (known as Oliver) at North Bristol NHS Trust was published by NHSE.

8.2 The independent review was chaired by Fiona Ritchie, OBE.

8.3 Twenty-one recommendations were made because of this review, 11 were specific to CCGs with regards to how they manage/conduct the LeDeR process locally.

8.4 Bury CCG has reviewed all the recommendations and is fully compliant with 9. For 2 of the recommendations the CCG is partially compliant as follows:

- There should be an assurance process with regard to providing regular, appropriately documented supervision for individual LeDeR reviewers.
- Each CCG must formally undertake and document and review its own systems and processes against the learnings and recommendations arising from Oliver's re-review.

Action – as preparations for the new national LeDeR system[13] begin, the CCG, along with the other Greater Manchester CCGs, will be assessing how reviewers will work

[13] From 1st April 2022, the new national LeDeR Policy and the new national arrangements in the NHS will mean local responsibility for the LeDeR programme will move from Bury CCG to the Greater Manchester local integrated care system (ICSs).

together and be supported, and how the assurance process will ensure quality and consistency.

9 Recommendation

9.1 The committee is asked to consider the findings of this report and note any issues to be addressed not already covered.

9.2 The committee is asked to confirm sharing of this report to Governing Body and publication on the CCG's website following any amendments that are required.

9.3 The committee is asked to support the publication on the CCG website of an easy read version of this Annual Report.

Carolyn Trembath
Head of Quality
June 2021