



**Wigan Borough**  
Clinical Commissioning Group

**Learning Disabilities Mortality Review (LeDeR) Programme**

**Annual Assurance Report 2020 – 2021**

**Wigan Borough**  
**Clinical Commissioning Group**

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## Introduction

1. This assurance report is the second written in respect of the Learning Disabilities Mortality Review Programme (LeDeR) within Wigan Borough. The report concerns the period 1<sup>st</sup> April 2020 until 31<sup>st</sup> March 2021.
2. The report provides an overview of LeDeR activity for 2020 – 2021 and analysis of the same. Commentary is provided regarding progress against the previous year's objectives and outlines the objectives for the forthcoming year.

## Background Information

3. The Learning Disabilities Mortality Review (LeDeR) Programme is delivered by the University of Bristol and follows the Confidential Enquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) that took place between 2010 – 2013. CIPOLD reported that for every person in the general population that dies from a cause of death amenable to good quality care, three people with learning disabilities will do so. CIPOLD also reported that on average, people with a learning disability live 20 years less than people without a learning disability.
4. One of the key recommendations of CIPOLD was for greater scrutiny of the deaths of people with learning disabilities. In this way, potentially modifiable circumstances leading to a death could be identified and avoided in the future through improvements to health and care services.
5. Reviewing the deaths of people with learning disabilities (aged 4 years and over) enables us to examine the circumstances leading to a death, identify best practice and the learning necessary to make improvements to health and social care, improve access to health and social care services and address the inequalities experienced by the learning disabled.
6. The review process applies to all people with learning disabilities and not just those known to health and social care services. Work has previously taken place locally and nationally with community based voluntary organisations and family/carers forums to notify and inform them of the LeDeR Programme.
7. The causes of death identified within the National LeDeR Annual Report alongside the findings from local reviews reflect the many challenges that people with a learning disability face. Nationally, LeDeR Annual Reports consistently report that men and women die far earlier when compared to the general population (23 and 27 years earlier respectively). Several years into the LeDeR Programme, National LeDeR Annual Reports continue to find evidence of bias in the care of people with learning disabilities resulting in unequal treatment.
8. Nationally and locally work continues in respect of sharing the learning and directing services to address the themes that arise from reviews with stakeholders working together with a view to improving services and reducing premature deaths. From a Wigan perspective, data in respect of and learning

from reviews has been presented to the Wigan Safeguarding Partnership (now Wigan Safeguarding Adults Board), Mental Health Programme Board, Learning Disability Partnership Board, Learning Disability and Autism Health Group, Quality Sub Committee (WBCCG) and Governing Body (WBCCG).

9. Local reviewers are responsible for undertaking reviews of the deaths of people with learning disabilities, who are registered with a GP within Wigan Borough. Reviewers come from a variety of backgrounds although the majority are nurses (either mental health or learning disabilities). NHS England (NHSE) and NHS Improvement (NHSI) have been unable to pay reviewers for this work or provide backfill to their respective organisations meaning that reviews were undertaken in addition to reviewers' substantive role and existing duties.

### **Multi-Agency Reviews**

10. The purpose of multi-agency reviews is to include the views of a broader range of people and agencies who have been involved in supporting the person who has died, where it is felt that further learning could be obtained from a more in-depth analysis of the circumstances leading up to the person's death.
11. Several circumstances indicate that a multi-agency review is required. These may be identified early in the review process or may emerge as the review progresses. A multi-agency review is always required:
  - Where the assessment of the care received by the person is graded as falling short of expected good practice and has significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death or care fell far short of expected good practice and this contributed to the cause of death.
  - When any red flag alert is indicated in the initial review and/or if there have been any concerns raised about the care of the person who has died.

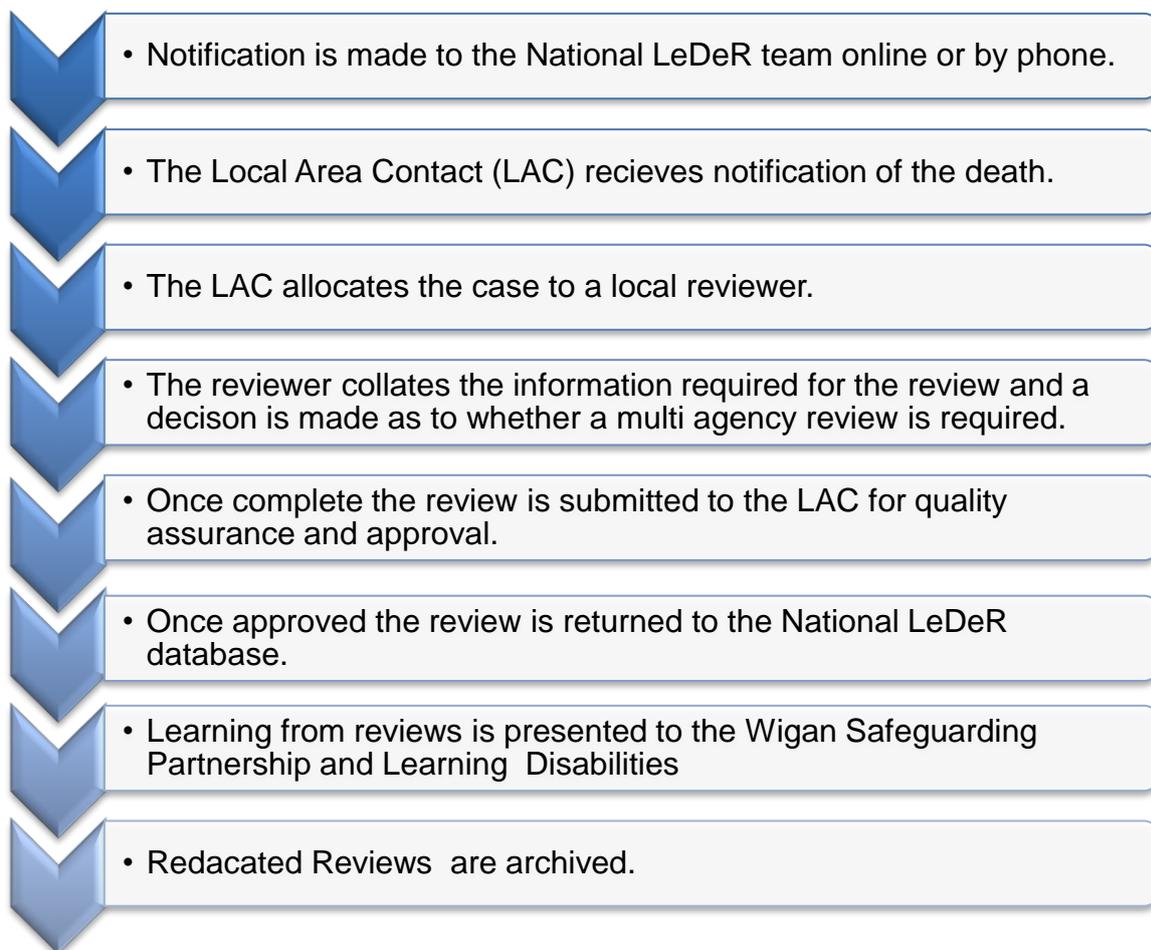
### **Confidentiality and Data Sharing**

12. The LeDeR programme has been given full approval to process patient identifiable information without consent. Specifically, this provides assurance for health and social care staff that the work of the LeDeR Programme has been scrutinised by the national Confidential Advisory Group (CAG). The CAG is appointed by the Health Research Authority to provide expert advice on the uses of data as set out in the relevant legislation and advises the Secretary of State for Health whether applications to process confidential patient information without consent should or should not be approved. The key purpose of the CAG is to protect and promote the interests of patients and the public whilst at the same time facilitating appropriate use of confidential patient information for purposes beyond direct patient care.

## Child Death Overview Panel (CDOP)

13. Safeguarding Children Partnerships are required to review the deaths of all children who reside in their local area and the regulations associated with the same are outlined in Working Together to Safeguard Children and the CDOP statutory and operational guidance. The purpose of the child death review process is to collect and analyse information about the death of each child who resides in Wigan Borough with a view to identifying any matters of concern or risk factors affecting the health, safety or welfare of children, or any wider public health concerns. There are several national programmes that focus on the review of child deaths or types of child death including the LeDeR process. However, CDOP supersedes the LeDeR process and the findings of the same always inform and influence LeDeR reviews in respect of children.

## LeDeR Process in Wigan



## Important Changes to LeDeR

14. The National LeDeR Team published a new LeDeR policy in June 2021 which is available on the NHS England website. Central to the new policy is stronger emphasis on the delivery of actions emerging from reviews and holding local systems to account for that delivery, to ensure that there is evidence of service improvement locally. NHSE and NHSI regional teams will hold Integrated Care Systems (ICSs) to account for the delivery of identified actions with ICSs reporting on them every quarter.
15. From the 1<sup>st</sup> of June 2021, there will be a new process for reviewers to follow, including a new computer system (web-based platform) and new training for the LeDeR workforce. Over the course of the next year, the workforce will change, and reviewers will work in teams so that no reviewer works in isolation. In addition, reviewers will be given the time and support needed to complete reviews. This is important and formed part of the recommendations of the Oliver McGowan Review conducted by Fiona Ritchie.
16. Moving forward, reviews will be undertaken for the first time of adults who have a diagnosis of autism but no learning disability. In addition, the process of review will change in that all notifications of a person's death will receive an initial review including talking to their family or people who knew them well, talking to their GP or looking at their GP records and talking to at least one other person involved in the person's care. If the reviewer feels that a more detailed review is required, a focused review will follow. Families are encouraged to say whether they think a focused review is required.
17. All people from BAME communities will have a focused review as the evidence base is clear in that the health inequalities experienced by people from these communities are significant. In addition, there is an evidence base to suggest that deaths from these communities are under reported.
18. The LeDeR Programme is just starting to collect data from the deaths of people with a diagnosis of autism and as such it is important that as much as possible is learnt from each of these reviews to establish a base line of data. All reviews of people with a diagnosis of autism will be focused reviews.
19. In response to the above changes to LeDeR, the new name for the LeDeR Programme is "Learning from Life and Death Reviews – people with a learning disability and autistic people". However, it is still acceptable to use the term LeDeR when referring to the programme or work related to the same.

## Data from Reviews

20. For the period 1<sup>st</sup> April 2020 – 31<sup>st</sup> March 2021, 41 notified deaths were subject to review and completed. Of the 41 reviews completed, 2 are progressing to Multi-Agency Review as per the review process given their poor gradings of care (5 and 6 respectively).
21. Regarding gender, 19 deaths were male (46.3%), and 22 deaths were female (53.7%).
22. The age spread at time of death of the 41 reviews completed is reflected in table 1.

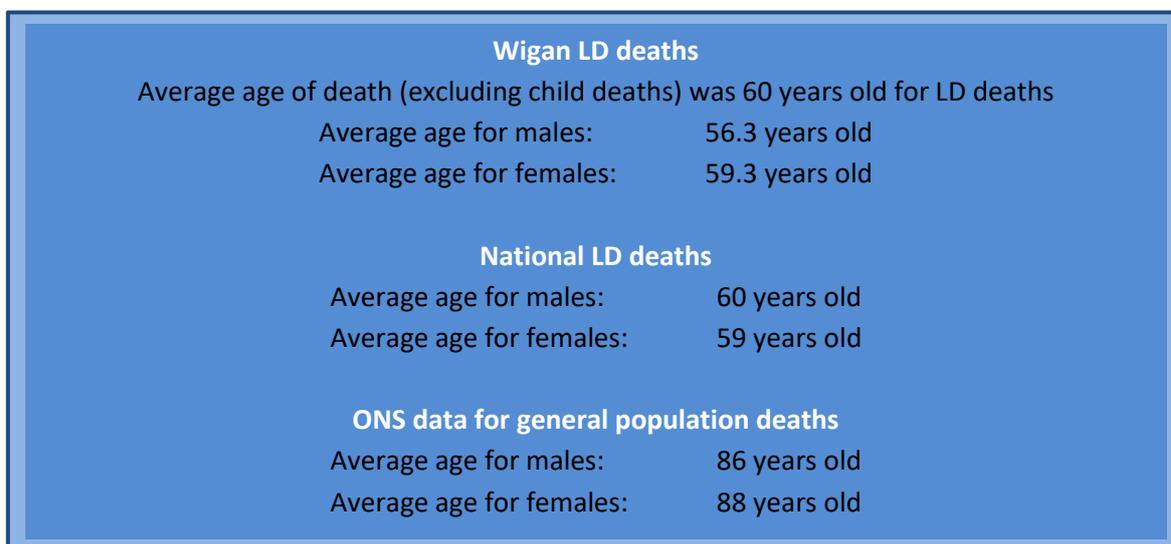
Table 1. Age at Time of Death

Age	0-10	11-20	21-30	31-40	41-50	51-60	61-70	71-80	81-90	91-100
Frequency	0	3	3	6	3	7	10	4	4	1

23. The Office of National Statistics (ONS) 2020 reported the average age of death in England for the general population to be 86 years for males and 88 years for females. However, in respect of people with learning disabilities, both the ONS and the LeDeR Programme in 2020 reported the average age at death for people with learning disabilities to be 60 for males and 59 for females, respectively. The average age at time of death for the reviews considered in this assurance report is 56.3 years for males and 59.3 years for females.
24. The average age at death for males and females in Wigan reflected within this assurance report is believed to be a more accurate figure than previously as it is based on a much greater number of reviews than the previous assurance report (38 adult deaths as opposed to 13 adult deaths). For clarity, calculation to determine the average age at death did not include the child deaths experienced during 2020-2021 as was the case in the previous assurance report.
25. In comparison to the previous assurance report, the average age at time of death for males in Wigan has increased slightly from 55 – 56.3 years although the average age at time of death for females has decreased significantly from 69 – 59.3 years. On first consideration, the decrease in age at death for females is concerning in that a decrease of approximately 10 years is clearly significant. However, the figure of 69 years was calculated from a much smaller number of reviews suggesting that it in some way provided a misleading figure. What can be said with the utmost certainty is that the average age at time of death for people with learning disabilities (both males and females) is far too low when compared to that of the general population confirming that much work remains to reduce what is an obvious health inequality.

26. The average age at time of death for people with learning disabilities for both Wigan and nationally is reflected in figure 1 along with the average age at time of death for the general population.

Figure 1. Average Age at Time of Death



27. The LeDeR review process requires reviewers to determine and record the level of learning disability experienced by the individual and this data is reflected in table 2 below. However, it should be noted that it is not always possible to determine the individual's level of learning disability for several different reasons for example, it is not clearly recorded within general practice, medical or nursing notes. In such cases, the level of learning disability is recorded as not known although every effort will have been made by the reviewer to determine the same.

Table 2. Level of Learning Disability

Level of LD	Mild	Moderate	Severe	Not Known
Frequency	10	20	7	4

28. Table 3 below records the living arrangements of the individuals subject to the review.

Table 3. Living Arrangement

Type of Accommodation	Supported Living	Family Home	Nursing Home	Residential Home	Sheltered Housing	Not Known
Frequency	11	20	4	1	1	4

29. The data in table 3 speaks for itself in terms of it being raw data about how many individuals subject to review lived in Supported Living, Nursing Homes, Residential Homes etc. However, on reflection the authors believe that the data is positive in the sense that 31 (75.6 %) of the individuals subject to review lived in a natural living arrangement such as Supported Living or their family home as opposed to a congregate setting such as a Nursing Home. This is encouraging in that living in a Supported Living arrangement or the family home is associated with increased choice, independence, community presence and person centredness.
30. An important part of the LeDeR review process is determining and recording the place of death of the individual subject to review and this information is reflected in Table 4 below. Whilst it is recognised that there may be times where hospitals are best placed (in terms of their medical expertise and facilities) to support people with learning disabilities at the end of their life, reviewers often receive feedback that families and carers require additional support and training to enable the person with learning disabilities to receive end of life care within their family home surrounded by their loved ones.
31. Of the 41 deaths subject to LeDeR review, the place of death was clearly recorded in 35 reviews. It is positive that 12 deaths occurred within the individual's own home (Supported Living and family home) as for many this is what we would wish for ourselves. However, the reviews recorded those 20 deaths out of the 35 where the place of death was known occurred in a hospital setting. On reflection, this figure seems high and suggests that there is much work to be done to increase the number of people with learning disabilities who receive end of life care within their own home. To better understand the end-of-life experience of the 20 individuals who died in hospital, the authors have taken an action to conduct an audit of the same including the cause of death and associated support and treatment of the same with a view to determining what it would take in terms of resource and training for the individual to have received end of life care at home.

Table 4. Place of Death

Place of Death	Hospital	Supported Living	Own/family home	Relatives Home	Nursing Home	Not known
Frequency	20	6	6	1	2	6

32. LeDeR was commissioned in 2015 with the aim of contributing to the improvement of quality of care and health outcomes for people with a learning disability. It is known that too many people with a learning disability die young and as the LeDeR programme continues more is understood about the circumstances that led up to those deaths. The LeDeR programme provides the largest body of evidence in the world about the deaths of people with a learning disability at an individual level.

33. The LeDeR review process requires that the cause of death be clearly recorded within the review. Table 5 below records the cause of death for the individuals subject to review for the period of this assurance report. To be clear, the first cause of death (1a) only has been used to inform and populate the table and as such the authors are mindful that the table represents “raw data” in relation to the cause of death. However, this is the first assurance report in which the cause of death has been reported upon and it is believed that the number of reviews (41) is large enough from which to draw some meaningful conclusions.

Table 5. Cause of Death

Cause of Death	Frequency
Covid 19	5
Sepsis	2
Cancer	3
Peritonitis	1
Brain Tumour	3
Cerebral Infarction	1
Raised Intra Cranial Pressure	1
Broncho Pneumonia	4
Pneumonia	6
Choking	1
Respiratory Failure	3
Traumatic Brain Injury	1
Aspiration Pneumonia	2
Cardiorespiratory Failure	1
Myocardial Infarction	1
Natural Cases (age related)	1
Not Known	4

34. Of the completed reviews (41), the cause of death has been determined and clearly recorded in 37 reviews. Where the cause of death is unknown it is because the death is yet to be determined via Coroner's Inquest. Unfortunately, the coronial process is currently experiencing significant delays due to the impact of the Covid 19 pandemic, and it is unlikely that the cause of death in the four outstanding reviews will be known until September 2021.
35. Respiratory conditions remain the most significant causes of premature mortality for people with a learning disability whose deaths have been reviewed as part of the LeDeR programme. The Action from Learning Report (LeDeR) 2019/20 reported that bacterial pneumonia was stated as a cause of death for 24% of adults and 20% of children who deaths were notified in 2019/20, with aspiration pneumonia cited in a further 17% of adult and 3% of children's deaths. In total, these respiratory conditions accounted for 2,162 deaths of people with a learning disability. Regarding respiratory conditions, the Wigan experience reflects the national experience in that 15 of the 37 reviews (40%) where the cause of death was known were attributed to respiratory conditions namely Broncho Pneumonia, Pneumonia, Aspiration Pneumonia and Respiratory Failure.
36. Sepsis is a life-threatening reaction to infection. It happens when your immune system overreacts to an infection and starts to damage your body's own tissues and organs. It is sometimes called septicaemia or blood poisoning. The Action from Learning Report (LeDeR) 2019/20 identified sepsis as the second leading cause of death for people with a learning disability whose deaths were reviewed as part of the programme. The Wigan experience in respect of sepsis does not reflect the national experience in that only 2 of the 37 reviews (5%) where the cause of death was known was attributed to sepsis. It is difficult to account for the difference in the number of deaths attributed to sepsis between the national experience and that of Wigan Borough. It has been suggested that work undertaken this past two years in respect of raising awareness of sepsis and its treatment has contributed to the reduction of sepsis deaths. However, to state this with any degree of certainty it will be necessary to monitor the number of sepsis deaths year on year and report the same within the annual assurance report.
37. According to the Action from Learning Report (LeDeR) 2019/20, the rate of deaths from cancer for people with a learning disability (13% for men and 15% for women in 2019) is half that of the general population. However, the report also reported that for deaths reviewed as part of the LeDeR programme, gaps in services and support for accessing cancer screening may have contributed to the death of 7% of people with a learning disability.

Table 6. DNACPR in Place

DNACPR in Place	Yes	No	Not Known
Frequency	21	15	2

38. Whilst there are some situations where do not attempt cardiopulmonary resuscitation (DNACPR) directions may be appropriate, concerns have been raised about instances in which a learning disability was cited as the reason for making a DNACPR order. As a result of this, the National Medical Director for NHS England and NHS Improvement, wrote an urgent letter to the NHS system reminding staff that a learning disability is not fatal and should never be used as a cause of death or the rationale for a DNACPR order.
39. The LeDeR Programme continues to work with the National Medical Examiner programme to ensure that learning disability is never cited as the cause of death on a death certificate. To the best of the authors knowledge, none of the completed reviews have cited learning disability as the cause of death.
40. Covid-19 heightened concerns about the use of DNACPR on a “blanket” basis and or without discussion with the person, their family or loved ones. On 7<sup>th</sup> April 2020, a joint letter from the National Medical Director and Chief Nursing Officer, NHS England and Improvement provided clarity regarding the use of DNACPR stating:
- “Each person is an individual whose needs and preferences must be taken account of individually. By contrast blanket policies are inappropriate whether due to medical condition, disability or age. This is particularly important regarding DNACPR orders, which should only ever be made on an individual basis and in consultation with the individual or their family”.
41. In considering the data from reviews, it appears that in general DNACPR guidance is being adhered to across the borough in that no concerns have been raised regarding the same. The number of individuals with a learning disability with a DNACPR order in place and those without a DNACPR order in place is appropriate when considering the different clinical presentation of the individuals. As the guidance makes clear, not every individual needs a DNACPR order not least if their medical condition does not warrant it. However, one aspect of DNACPR orders and application of the same that would benefit from audit is whether the family of the individual have been consulted in the process and whether the capacity of the individual in terms of understanding the decision being made has been assessed. Moving forward, the Local Area Contact plans to audit a sample of reviews in respect of whether the application of DNACPR orders has followed best practice presenting the results to the Quality Sub Committee.

Table 7. Main Carer

Main Carer	Family	Paid Support	Not Known
Frequency	13	25	3

42. LeDer reviews are required wherever possible to record the main carer of the person with a learning disability in terms of whether the individual was cared for by their family or received paid support. As such, the data in respect of the same speaks for itself and is for information only as it does not require further analysis.

Table 8. Antipsychotic Medication

Antipsychotic Medication Prescribed	Yes	No	Not Known
Frequency	11	24	6

43. LeDer reviews are required wherever possible to record whether the person with a learning disability was prescribed antipsychotic medication. The background to this is that it is often reported that people with learning disabilities are more likely than the general population to be prescribed antipsychotic medication often in the absence of them having a psychotic condition. Nowhere is this better illustrated than in the sad and potentially avoidable death of Oliver McGowan who died further to being given Olanzapine despite he and his family informing doctors that he had reacted badly to it in the past. Oliver's death received national attention in the media and highlighted what is a significant concern for the families of people with learning disabilities.
44. This is the first time that the prescribing of antipsychotic medication has been included in this report meaning that there is no previous data about the same to enable comparison. However, the authors believe that the fact that only 11 individuals out of 41 were prescribed antipsychotic medication suggests that it is not a widespread practice across the borough. It should be noted that in 2 reviews it was reported that although the individual was prescribed an antipsychotic it was for used for its properties as an antiemetic which was clearly recorded in the individual's health record.

Table 9. Antidepressant Medication

Antidepressant Medication Prescribed	Yes	No	Not Known
Frequency	11	25	5

45. As above, this is the first time that the prescribing of antidepressant medication has been included in this report. The raw data is encouraging in that it does not suggest that prescribing of antidepressant for people with learning disabilities is a widespread practice.

46. LeDeR reviews require that the reviewer, based on the information that they have gathered and analysed via the review process, grade the quality of care received by the deceased. The grading reflects the overall experience of services as opposed to one organisation's input or contribution to care. The grading of the quality of care received by the deceased applies only to adult LeDeR reviews and the reviewer must select one of the six possible gradings illustrated in table 10.

Table 10. Gradings of Care Descriptors

Grading	Descriptor
1.	This was excellent care (it exceeded good practice).
2.	This was good care (it met expected practice).
3.	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).
4.	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.
5.	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.
6.	Care fell far short of expected good practice and this contributed to the cause of death.

47. The gradings of care in table 11 relate to the reviews of adult deaths only (38 in total) as child deaths are subject to the CDOP process and do not require a reviewer to grade the quality of care received by the deceased. As an absolute minimum, people with learning disabilities should expect the care and support that they receive to be satisfactory. However, it is not unreasonable for people with learning disabilities and their families to expect the care and support that they receive to be of a good standard as this is the expectation that the general population have when accessing health and social care services. From an aspirational perspective, health and social care professionals want people with learning disabilities to experience excellent care every time they access services although it is recognised that there is much work to be done to achieve this particularly in respect of reducing the health inequalities experienced by the learning disabled.
48. Table 11 illustrates that of the 38 adult reviews completed during the reporting period, 31 (81.5%) received a grading commensurate with having received either satisfactory, good or excellent care. Specifically, 12 (31.5%) received a grading of having received satisfactory care, 15 (39.4%) received a grading of having received good care and 4 (10.5%) received a grading of having received excellent care.

50. Table 11 also illustrates that of the 38 adult reviews completed during the reporting period, 7 (18.4%) received a grading commensurate with having received care that fell short of expected practice which in some cases was believed to contribute to the cause of death. Clearly such care and poor gradings of the same is unacceptable.

Table 11. Grading of Care

Grading of Care	1	2	3	4	5	6
Frequency	4	15	12	3	3	1

49. It is the authors belief, that the gradings in respect of good and excellent care, 19 (50%) in total reflect well on the health and care services provided to the person with a learning disability and the staff who work within them. However, much work remains to improve the experience of people with learning disabilities when accessing health and social care services as the figure of 50% is too low. Moving forward, it is planned to target issues such as reasonable adjustments, Health Action Plans, improving communication, improving advocacy etc as by doing so it is hoped to drive the grading of satisfactory to good.
50. LeDeR reviews require that the families of the deceased be given the opportunity to contribute to the review. The knowledge and experience of families is crucial in terms of better understanding the experience of the deceased and capturing the learning to drive quality and improve the future experience of people with learning disabilities when accessing health and social care services.
51. The data in table 12 is believed to be self-explanatory. Clearly, it would be advantageous to the LeDeR programme if more families were actively engaged in the review process. However, the reasons for families not wishing to participate are both numerous and varied. In the context of this reporting period, several families felt unable to participate in the review process as they were bereaved, in several reviews, reviewers were, despite their best efforts, unable to identify a next of kin and in several reviews, notably when the deceased was elderly, there was no next of kin.
52. Regarding instances where families felt unable to contribute to the review process due to being bereaved, it should be noted that LeDeR reviews are often commenced within a relatively short period of the person with a learning disability passing. Reviewers are mindful of the needs of families at such a sensitive time and the matter of asking families if they wish to contribute to the review is done so with sensitivity and respect.

Table 12. Family Involvement in Review

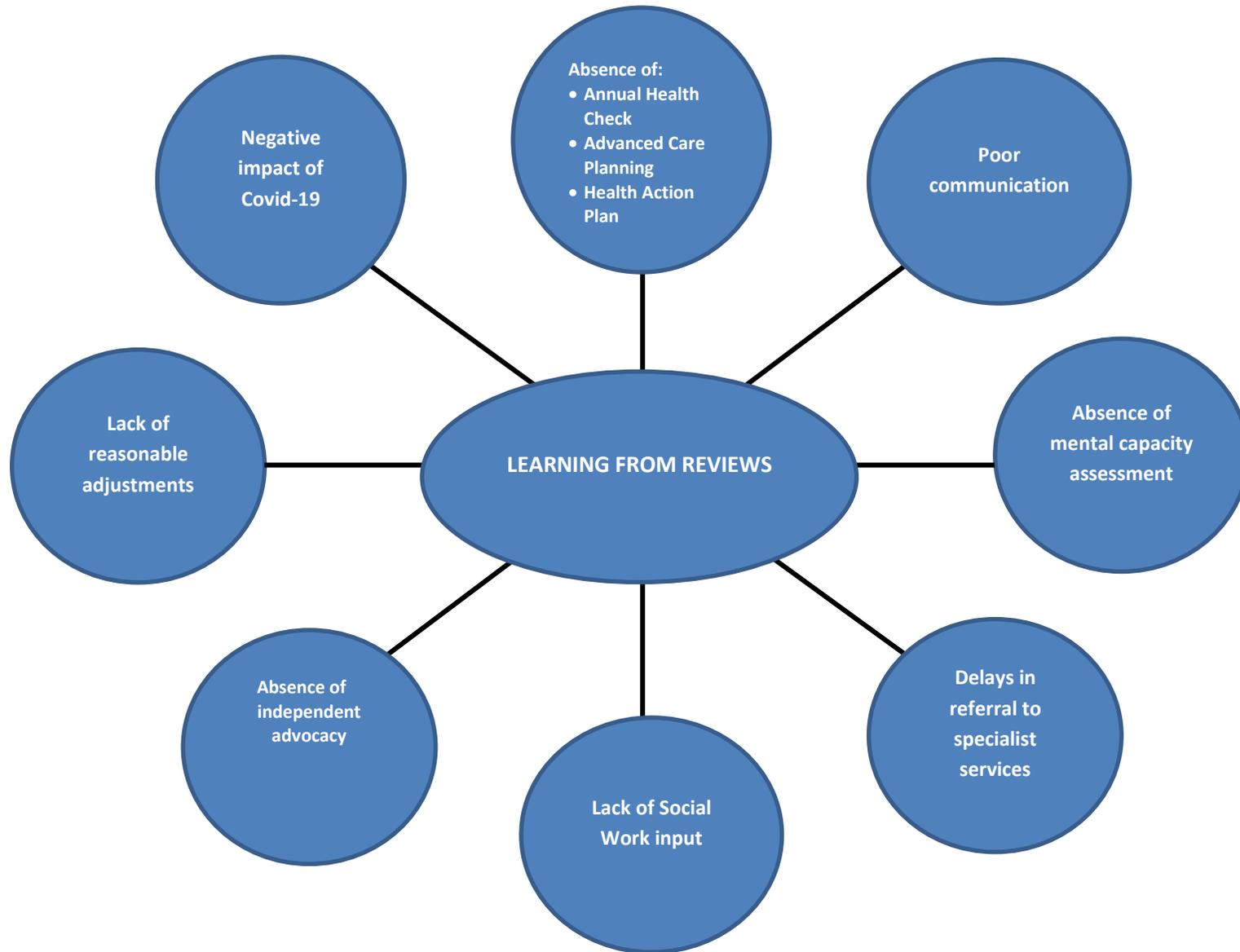
Family Involvement	Yes	No	Children's Review
Frequency	13	25	3

## Learning

53. The most important part of the LeDeR review process is capturing the learning to emerge from reviews in order that it can be shared across the health and social care economy to improve clinical practice and the quality of service that people with learning disabilities receive. It should be noted that the learning to emerge from reviews is often associated with or perceived to be a failing primarily because the review process, whilst reporting good practice, also seeks to identify areas for improvement in the delivery of care to people with learning disabilities. The good practice to emerge from reviews is reported separately in the next section of this report.
54. To provide informed comment and draw meaningful conclusions from the learning to emerge from reviews it has been necessary to undertake a detailed analysis of the same. To achieve this, the authors of this report adopted a five-stage process of thematic analysis; familiarisation with data, generating codes, searching for themes, reviewing themes, and defining themes (Braunn & Clarke, 2006). On completion of the analysis a thematic map was developed to provide a visual representation of the learning to emerge from reviews. Themes were reviewed in terms of whether there was enough data to support them before developing the thematic map and themes were named capturing their fundamental nature to ensure clarity.
55. The most common theme to emerge from reviews (in terms of learning), and being supported by the most data, was the absence of learning disability specific clinical documentation and processes. Of the 38 adult reviews undertaken during the period of this report, 9 reported the absence of clinical documentation such as Health Action Plans, Hospital Passports and Advanced Care Plans and the absence of processes such as Annual Health Checks.
56. The second most common theme to emerge from reviews was poor communication. This is considered unsurprising as poor communication is often cited within health and social care reviews, investigations, enquiries etc as a key failing. The context to this theme is that 6 reviews reported a lack of easy read information being available to the person with a learning disability. A further review reported the inability of some people with learning disabilities to articulate when they are in pain requires correct assessment for example using the Abbey Pain Scale which did not happen in the specific review. The authors note that it could be argued that the absence of easy read information could sit within the absence of learning disability specific clinical documentation and processes' theme. However, in the context of the individual reviews the authors are clear that the fundamental issue was one of poor communication.

57. The absence of mental capacity assessment or such assessments not following best practice emerged as a theme in 6 reviews. This is considered disappointing given that the Mental Capacity Act has been in place since 2005 and operational since 2007. However, the authors noted that in several reviews the issues relating to the assessment of capacity were genuinely complex requiring a collaborative approach from partners.
58. Delays in referral to specialist services also emerged as a theme in 6 reviews. To be clear, the context of this theme included not just a delay in referral but in 2 specific reviews, delays in accessing a formal diagnosis and the appropriate support and treatment. As above, the authors noted the complexity of some of the reviews in terms of the individual's physical presentation which often required referral to several specialist services.
59. A lack of social work input emerged as a theme in 5 reviews. This theme often related to the lack of a carer's assessment having been undertaken in the individual's care. Moving forward it is planned to raise awareness of this issue via the LeDeR bulletin produced by the Local Area Contact.
60. Four reviews reported the absence of an independent advocate in the care and support received by the person with a learning disability. To be clear, there were some good examples of individuals being supported by an independent advocate within reviews, but independent advocacy should be available to all and as above this issue will be highlighted in the LeDeR bulletin.
61. A lack of reasonable adjustments having been made in the person with a learning disability's care and support emerged as a theme in 3 reviews. Changing how we work to develop clinical pathways and improve care has been a key workstream of the LeDeR programme. In addition, NHS Improvement's learning disability improvement standards include a requirement for all Trusts to make reasonable adjustments for people with a learning disability. The context of this theme is that 2 reviews noted the lack of reasonable adjustments made to facilitate health screening whilst 1 reported that the individual had not been recorded by the hospital as having a learning disability resulting in no consideration being given to the need to make reasonable adjustments.
62. The final theme to emerge from reviews in terms of learning is that of the negative impact of Covid-19 during the period of this report. The learning related to 2 reviews, specifically, the difficulties in accessing patient records during the pandemic to complete LeDeR reviews and, the negative impact of visitors not being allowed to visit hospital during the pandemic resulting in the person with a learning disability feeling increasingly isolated. These issues have been previously reported to the Quality Sub Committee during the first wave of the pandemic.

Figure 2. Learning to Emerge from Reviews



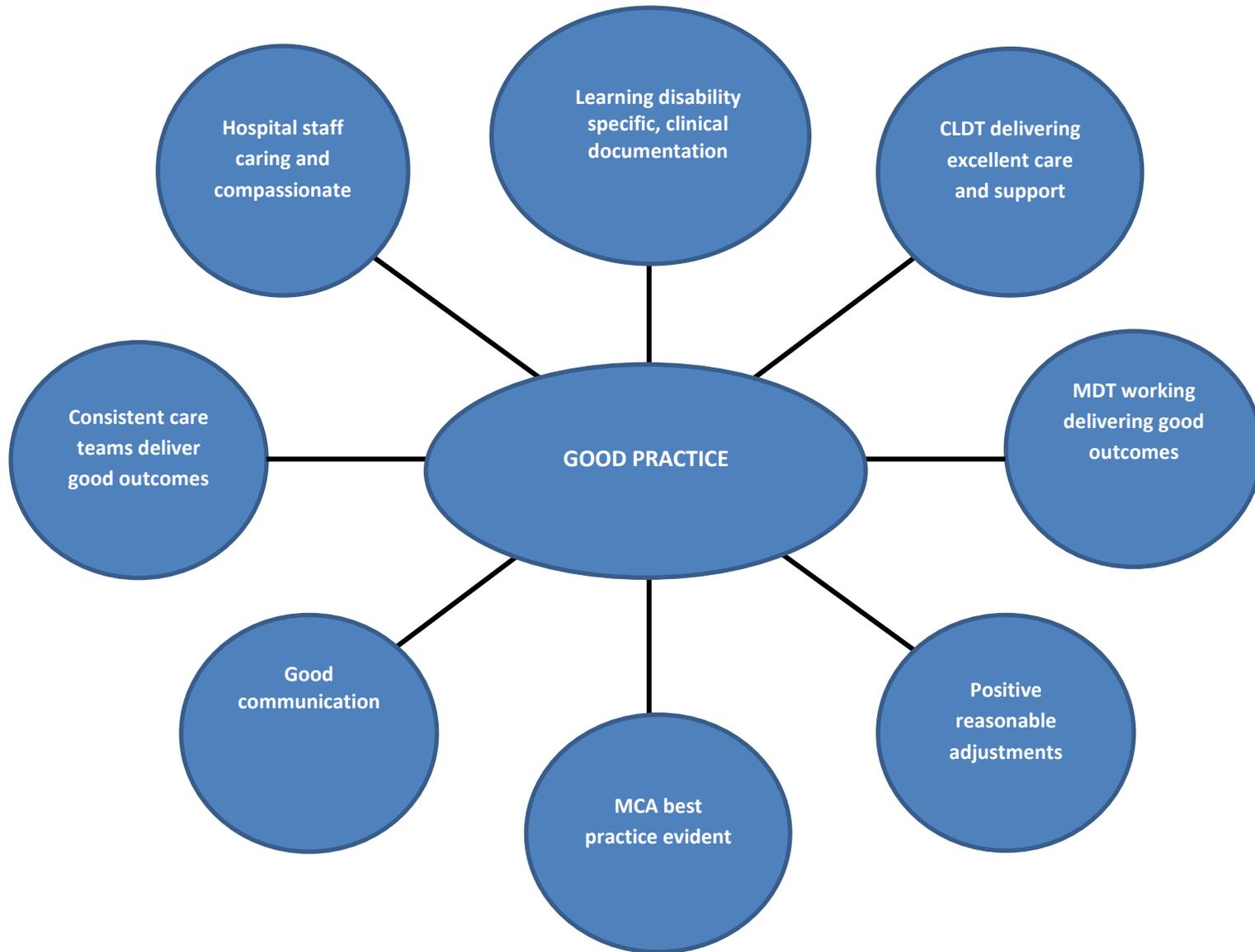
## Good Practice

63. As with the learning to emerge from reviews, the authors have undertaken an analysis of the good practice identified from reviews using the same five stage process of thematic analysis outlined above (39).
64. The most common theme in respect of good practice and in terms of being supported by the most data was that of good quality, learning disability specific, clinical documentation. Nine reviews reported that the person with a learning disability had in place either a good quality Hospital Passport, Communication Passport, Health Action Plan or Hospital Avoidance Plan. The presence of these documents was clearly associated with the delivery of good quality care and the delivery of good clinical outcomes for the individual with a learning disability.
65. The second most common theme identified from reviews in terms of good practice was that of the Community Learning Disability Team (CLDT) delivering excellent care and support. Six reviews highlighted the positive work of the CLDT and importantly this feedback often came direct from families who contributed to the review process. The expertise of the CLDT was viewed as a strength by both fellow professionals and families particularly regarding clinical assessment.
66. Multi-disciplinary team working emerged as a strong theme with 5 reviews reporting that the collaborative nature of multi-disciplinary team working delivered good outcomes for people with learning disabilities. Three reviews attributed multi-disciplinary working to enabling the individual to live as independently as possible in their own home. The findings in respect of multi-disciplinary working, specifically the collaborative nature of the same, are considered pertinent not least in the context of the development of an Integrated Care System a strength of which is collaborative working between professionals.
67. Four reviews identified good practice in terms of reasonable adjustments being made to deliver care and support to people with learning disabilities. As described above, reasonable adjustments are a key workstream of the LeDeR programme and something which the Local Area Contact will be focusing on over the course of the next year in terms of raising awareness of the same not just within hospital settings but across community settings and primary care also.
68. Four reviews identified good practice in respect of implementing the Mental Capacity Act, specifically the assessment of capacity. This involved practice such as clearly recording within the individual's medical record that they lacked capacity, best interests meeting being held, the individual being involved in decision making relating to their care and treatment and using an Independent Mental Capacity Advocate to advise and support the decision-making process.
69. Three reviews reported good practice in respect of communication. The context of this theme was that the reviews reported that easy read information was

provided to the individual with a learning disability and their family in respect of Covid-19 and the impact of the same upon the admission process.

70. The remaining themes were supported by the same amount of data. Two reviews each reported good practice in respect of a consistent care team delivering good quality care and hospital staff being caring and compassionate toward the person with a learning disability during their admission.

Figure 3. Good Practice to Emerge from Reviews



## Bulletins

71. 5A key development this past year has been the development by the Local Area Contact of a LeDeR bulletin the purpose of which has been to keep the health and social care economy informed of how LeDeR reviews are progressing and the learning to emerge from them.
72. To date, bulletins have covered topics including the learning to emerge from the first 15 completed reviews, the deaths of people identified as having a learning disability from Covid-19 and the factors affecting the risk of the same, demographic information and the learning to emerge from review for the period that coincided with the first pandemic and changes to the LeDeR programme and process.
73. Moving forward, it is hoped during the next year to widen the bulletin audience to share learning, inform practice and drive the quality of care delivered to people with learning disabilities across the Borough. Suggested topics for future bulletins include reasonable adjustments, Health Action Plans, DNACPR order guidance and the prescription of anti-psychotic medication.

## Performance Against Objectives

74. Performance against the objectives set in 2020-2021 has, despite the negative impact of Covid-19, been largely positive in that:
  - The number of reviewers has increased with 3 new reviewers having been trained and commenced reviews. The capacity of the pool of reviewers has increased resulting in a greater number of reviews being completed.
  - A local Steering Group has been formed and meets on a quarterly basis although moving forward from September 2021 it will meet on a bi-monthly basis. The Steering Group has been useful in terms of information sharing, improving the process of conducting reviews, and keeping the LeDeR agenda active.
  - The Local Area Contact (LAC) has attended the Learning Disability and Autism Task Group to update regarding reviews and the learning to emerge from the same.
  - Several papers have been taken to the Quality Sub Committee regarding LeDeR during the period of this report. Specifically, papers have been presented regarding general LeDeR activity and in respect of the deaths that occurred during the first wave of the pandemic and the learning to emerge from the same.
  - A cohort of 13 reviews that occurred during the pandemic were completed ahead of the deadline set by NHSE and the learning to emerge from the same shared with key partners across the health and social care economy.

75. Unfortunately, the impact of Covid-19 meant that some objectives were unable to be delivered. For example, the restrictions put in place by the government in respect of social distancing meant that we were unable to hold a local LeDeR event to capture the experience of people with learning disabilities accessing primary care services. Similarly, the impact of Covid-19 has been such that resources have been redirected to the fast-track completion of reviews that occurred during the pandemic as per the NSHE directive. As a result of this, the objective regarding the identification and delivery of “end of life” training for carers and families has not been delivered, although will be prioritised for 2021 – 2022.

## **Moving Forward**

76. Regarding objectives for 2021-2022, a directive from the National LeDeR Team has made clear that the emphasis moving forward is to ensure the delivery of actions from reviews and to evidence service improvement from a local perspective. This therefore will form the basis of and be the driver for objectives this next year including:
- The development of a “Learning into Practice” group which will replace the current Steering Group and whose focus will be entirely driven by ensuring that the actions to emerge from reviews are delivered in a timely manner.
  - The continued implementation of a LeDeR bulletin (monthly) to inform and improve practice in respect of supporting people with learning disabilities. The impact of bulletins in terms of how well they inform and improve practice is to be measured by the implementation of a questionnaire with results reported to the Quality Sub Committee.
  - The development of a programme of audit directly related to LeDeR activity with results also presented to the Quality Sub Committee. For example, this might include auditing practice related to people with a learning disability subject to a LeDeR review and whether their capacity had been assessed in keeping with best practice.
  - The identification and delivery of end-of-life training for carers and families.
  - The delivery of the WSAB Organisational Safeguarding Sub-Group work stream in respect of reasonable adjustments and developing a better understanding of borough wide practice in respect of the same.

## **Conclusion**

77. The LeDeR programme remains well established and indeed continues to progress in Wigan. The number of reviewers has increased as has their capacity to undertake reviews and experience in respect of the same. This past year has seen a significant increase in the number of reviews completed by reviewers and the learning to emerge from reviews has been shared with colleagues across the health and social care economy in a timely manner.

Moving forward, our priority is to translate the learning from reviews into practice, to improve the quality of care and/or service delivered to people with a learning disability. Crucially, this will be led by the Learning into Practice Group and by continued partnership working with health and social care colleagues across the Borough.

Reuben Furlong, Assistant Director of Safeguarding – Adults

Jenny Simpson, Safeguarding Manager - Adults