The Learning Disabilities Mortality Review (LeDeR) Programme

University of BRISTOL

Annual Report 2019

University of Bristol Norah Fry Centre for Disability Studies

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Acknowledgements and credits

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https://lukasziskierka.com

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HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing, and National Voices. Its aim is to promote quality improvement in patient outcomes.

The NCAPOP, which encompass confidential enquiries, is designed to help assess the quality of healthcare, and stimulate improvement in safety and effectiveness by systematically enabling clinicians, managers, and policy makers to learn from adverse events and other relevant data.

HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies. For more information see:
www.hqip.org.uk/national-programmes .

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Foreword

This is the fourth annual report of the English Learning Disabilities Mortality Review (LeDeR) programme. It presents information about the deaths of people with learning disabilities aged 4 years and over notified to the programme from 1st July 2016 – 31st December 2019. The central focus of this year's report is on deaths for which a review was completed during the last calendar year (1st January – 31st December 2019).

We start the report by sharing brief glimpses of some of the people whose deaths have been reviewed by the LeDeR programme during 2019 – those at the centre of this report.

Chapter 1 provides a brief overview of the LeDeR programme and a summary of the number of deaths notified, and reviews completed – those at the centre of this report.

Chapter 2 describes the people with learning disabilities who died and whose deaths have been notified to the LeDeR programme. The focus is on their demographic details, the range of medical conditions they were known to have, and the medications they were usually prescribed.

Chapter 3 provides information about the deaths of people with learning disabilities, in terms of their age at death, place of death, month of death, and cause of death. We also consider the proportion of deaths that were reported to a coroner, and those with an decision not to resuscitate the person should their heart stop.

Chapter 4 focuses on indicators of the quality of care for adults with learning disabilities whose deaths were reviewed in 2019. We consider examples of best practice provided, and a range of other indicators of the quality of care provided. The chapter concludes by presenting the overall grade ascribed by reviewers for the quality of care provided.

Chapter 5 provides a focus on a variety of specific issues. Most relate to deaths from specific medical conditions (pneumonia, epilepsy, sepsis) or groups of conditions (urgent or emergency care sensitive conditions); others are about deaths in particular age groups (children aged 4-17; young people aged 18-24 years; adults aged 75 years and over), or that have a specific issue as the common theme (family involvement in decision-making).

Chapter 6 draws together recommendations and conclusions. It provides an indication for policy makers and practitioners about where improvements in the care of people with learning disabilities could lead to greatest benefit.

Glossary of abbreviations used

A&E	Accident and Emergency department
ACSC	Ambulatory Care Sensitive Conditions
ADASS	Association of Directors of Adult Social Services
ADCS	Association of Directors of Children's Services
BAME	Black, Asian and Minority Ethnic group
CIPOLD	Confidential Inquiry into Premature Deaths of People with Learning Disabilities
CLDT	Community Learning Disability Team
CPR	Cardio-Pulmonary Resuscitation
CQC	Care Quality Commission
CQUIN	Commissioning for Quality and Innovation
DHSC	Department of Health and Social Care
DNACPR	Do Not Attempt Cardio-Pulmonary Resuscitation
DVT	Deep Vein Thrombosis
HEE	Health Education England
ICD-10	International Classification of Diseases version 10
ITU	Intensive Therapy Unit
LeDeR	Learning Disabilities Mortality Review programme
LHCRE	Local Health and Care Record Exemplars
MCA	Mental Capacity Act
MCCD	Medical Certificate of Cause of Death
NCAPOP	National Clinical Audit and Patient Outcomes Programme
NECS	North East Commissioning Support Group
NICE	National Institute of Clinical Excellence
ONS	Office for National Statistics
PE	Pulmonary Embolism
PEG	Percutaneous Endoscopic Gastrostomy
SCIE	Social Care Institute for Excellence
SCR	Summary Care Record
SUDEP	Sudden Unexpected Death in Epilepsy
UCSC	Urgent Care Sensitive Conditions

Some of the people who have died

This report is about people who have died. They are people who matter.

In writing this report we want to avoid people becoming impersonal numbers. We are therefore starting this report, as we did with our previous annual report, by sharing brief glimpses of some of the people whose deaths have been reviewed by the LeDeR programme during 2019.

All details have been anonymised[1], but the stories are those as told by families or paid carers to reviewers. We would like to thank the many families who have given us permission to use their stories.

Andrew, died aged 19 from pneumonia

Andrew was a friendly and outgoing person who loved to laugh and spend time with people. He was described as having a 'sunny nature' and a positive impact on those who supported him. Andrew took part in many activities that brought him joy including swimming, drumming, singing and going on regular ski trips with his family.

Raymond, died aged 71 from congestive cardiac failure

Raymond was described as strong willed and independent. He lived in his own flat with support and would visit his girlfriend at weekends. He sometimes felt lonely and was considering the idea of moving to live with other people. Raymond did not eat the best diet, often preferring sweets and grapes.

Mary, died aged 53 from cancer of the liver and pancreas

Mary was described as a lovely, friendly person with a great sense of humour. She lived with her husband whom she had met at a community centre. Mary enjoyed going to football matches with her husband and spending time with her sister and brother in-law. She enjoyed doing puzzles and watching comedies – she would roar with laughter whilst watching 1970s comedy shows.

Sharon, died aged 56 from dementia

Sharon had lots of friends and an active social life. She attended church, the local day service and had 2 voluntary jobs. She loved music and going shopping to look for bargains. Sharon had lived in the same area all her life and was very happy and settled there. She had lived with her family for the first half of her life, she then lived in a residential home, remaining close to her family.

Trevor, died aged 69 from acute renal failure

Trevor was fun-loving and happy. He paid particular attention to his appearance, often wearing a brightly coloured tie from his collection. Trevor lived in a group home, feeling a strong sense of belonging. He participated in all activities and events and formed particularly close friendships with two of the other people that lived there.

[1]Please note that all names throughout this report have been changed to protect confidentiality.

Contents

Executive summary

This is the fourth annual report of the Learning Disabilities Mortality Review (LeDeR) programme.

It presents information about the deaths of people with learning disabilities aged 4 years and over notified to the LeDeR programme from 1st July 2016 - 31st December 2019, with a focus on deaths reviewed during 2019[2].

Deaths notified to the programme
From 1st July 2016 - 31st December 2019, 7,145 deaths were notified to the programme (6,629 were adults and 516 were children aged 4-17 years).
By 31st December 2019, the review process had been completed for 45% of these deaths. Of the reviews completed in 2019, 6% had received a full multi-agency review.

The people whose deaths were notified
Of those whose deaths were notified, 58% were males; 90% were white British; 30% were known to have had mild learning disabilities, 33% had moderate learning disabilities, 27% severe learning disabilities and 10% profound and multiple learning disabilities.

People from BAME groups died disproportionately at younger ages than white British people. Of those who died in childhood (ages 4-17 years), 43% were from BAME groups.

People with profound and multiple learning disabilities also disproportionately died at younger ages. Of those who died in childhood, 46% had profound and multiple learning disabilities.

Almost all (94%) of those whose death had been reviewed had at least one long-term health condition. The mean number of long-term health conditions was three. Most (97%) of the adults whose death had been reviewed had usually been prescribed one or more medications. The mean (average) number of usually prescribed medications was 5.8 (range 0 – 21). Almost a quarter (22%) of people had been prescribed Sodium Valproate, a drug given to treat epilepsy or bipolar disorder.

Age at death
In 2018, the majority (85%) of people in the UK population died aged 65 and over. The corresponding proportion of people with learning disabilities was 37%.

For deaths notified in 2019, the median (average) age at death was 61 for males and 59 for females, an increase of 1 year for males since 2018.

Our updated data suggest that the disparity between the age at death for people with learning disabilities (age 4 years and over) and the general population (all ages) in 2019 was 22 years for males and 27 years for females. There is a reduction of one year in the disparity between the age at death of men with learning disabilities compared with men in the general population.

Month of death
There was a greater proportion of deaths of people with learning disabilities from October – December than in the general population.

Place of death
The proportion of people with learning disabilities dying in hospital was 60% in 2019; a slightly smaller proportion than

[2] Please note that small numbers of fewer than five have been suppressed throughout the report where the protection of confidentiality is required.

the 62% reported in our last annual report. In the general population it was 46% in 2018.

Deaths of people in contact with specialist mental health services
Of the deaths reviewed in 2019, nine people were either a current inpatient at the time they died or had been discharged less than two months prior to their death. Issues identified in these deaths included a lack of attention to physical health issues, poor care coordination, a lack of holistic care provision, and a lack of supervision or observation.

Deaths reported to a coroner
Deaths of people with learning disabilities were reported to a coroner much less frequently (32% of adults) than people in the general population (41% of adults and children).

Do not attempt cardio-pulmonary resuscitation (DNACPR) decision
Of the deaths reviewed in 2019, 72% had a DNACPR decision. Reviewers felt that the majority of these (78%) were appropriate, correctly completed and followed.

Causes of death
Concerns have been raised about the accuracy of the coding of the underlying causes of death in people with learning disabilities, nationally and internationally. Once again, our data reinforce these concerns.

In people with learning disabilities, the most frequent causes of death by ICD-10 chapter were diseases of the respiratory system (20%), diseases of the circulatory system (15%) and congenital and chromosomal abnormalities (14%).

Coding underlying causes of death as being from congenital and chromosomal causes, as we commented in our last annual report, conceals the more specific causal sequence of events leading to the person's death. Other causes of death mentioned in Part I of the MCCD for people whose underlying cause of death was attributed to Down's syndrome were dementia or Alzheimer's disease (46%), bacterial pneumonia (33%) and aspiration pneumonia (27%).

The individual medical conditions most frequently cited anywhere in Part I of the MCCD (not solely as an underlying cause of death) were pneumonia and aspiration pneumonia.

Avoidable medical causes of death
People with learning disabilities died from an avoidable medical cause of death twice as frequently as people in the general population (44% of deaths of people with learning disabilities; 22% of deaths in the general population).

The greatest difference between people with learning disabilities and the general population was in relation to medical causes of death which are treatable with access to timely and effective healthcare. A third (34%) of deaths of people with learning disabilities were from treatable medical causes, compared to 8% in the general population – a four-fold difference.

The age-standardised avoidable mortality rate for people with learning disabilities was 520 (per 100,000) compared to 227 for the general population. The majority of this excess mortality was due to treatable, rather than preventable, causes. Treatable causes accounted for 403 per 100,000 deaths in people with learning disabilities, compared with 83 per 100,000 deaths in the general population.

Indicators of the quality of care

A greater proportion of reviewers provided examples of best practice in 2019 (54%) than in 2018 (33%), but otherwise the proportions for each of the indicators of quality of care were similar across the time periods.

Best practice

Just over half (54%) of reviews reported one or more examples of best practice. These were frequently in relation to:

- Person-centred care.
- Multi-agency working.
- Advocacy.
- The use of reasonable adjustments.

Problematic aspects of care

One in ten reviews (12%) noted that concerns had been raised about the person's death. These were commonly in relation to:

- Delays in diagnosing and treating illness.
- An apparent lack of care.
- Unsafe discharges from hospital.
- The quality of health or social care received by the person.
- Assumptions made about the person.

Delays in the person's care or treatment that adversely affected their health were reported in 13% of reviews. Common themes were:

- Delays in appropriate investigations being carried out.
- Delays in the timely provision of medical care.
- Delays in processes related to the Mental Capacity Act.

Problems with organisational systems and processes were reported in 13% of reviews. Many of the problems related to the poor coordination of care and information sharing within and across different agencies.

Gaps in service provision that may have contributed to the death of a person were reported in 7% of reviews. Such gaps included:

- A lack of, or non-referral to, specialist learning disability services.
- A lack of care coordination.
- Out of date social care assessments.

Overall assessment of the quality of care provided

A greater proportion of deaths reviewed in 2019 (56%) reported that the person had received care that met or exceeded good practice, compared with deaths reviewed in 2018 (48%).

A similar proportion of adults in 2019 (7%) as in 2018 (8%) were reported to have received such poor-quality care that it significantly impacted on their well-being and/or had the potential to, or actually did, contribute to their cause of death.

The reasons for falling so far short of expected good practice varied, but predominantly included:

- Problems with care that were related to significant delays in the diagnosis and treatment of illness.
- Omissions in care.

Multi-agency review

Multi-agency panels reviewed 117 deaths in 2019.

Potentially avoidable contributory factors to a death relating to the person's care and its provision were identified in 61% (n=71) of deaths reviewed by a multi-agency meeting. These included issues relating to:

- The provision of appropriate nutrition.
- Failure to recognise or respond appropriately to early signs of deterioration.
- Errors or omissions in the provision of care.

Potentially avoidable contributory factors relating to the way services were organised and accessed were identified in 62% (n=73) of deaths reviewed by a multi-agency meeting. These included issues relating to:

- How different agencies worked together to support an individual.
- The training needs of staff.
- Clarification for staff about how to follow the Mental Capacity Act in practice.

Overall, almost half of panels (49%) concluded that the death was not potentially avoidable; 31% felt that the death was potentially avoidable. The panel could not reach a unanimous decision on 20% and the question was unanswered by fewer than five panels.

Focus on specific issues

Family involvement in decision making via formal Best Interests processes

The 'Best Interests' decision-making process, as stipulated by the Mental Capacity Act, requires consultation with close relatives or friends (and a range of others) if the person lacks the capacity to make a specific decision for themselves.

The majority of completed reviews referred to some family involvement in decision making. However, there were also examples of instances where Best Interests processes were not followed, either because there was an over-reliance on the views of family members, or families were excluded from the decision-making process. Apparent challenges for some professionals included:

- Difficulty in contacting a family member.
- The appropriateness of some family members.
- Disagreements between family members.
- Ensuring that families understood the decisions to made.

The families we consulted identified recommendations to strengthen the understanding of, and adherence to the Mental Capacity Act. These are included in Chapter 6.

Deaths from pneumonia

Of the deaths notified in 2019, 24% of adults and 20% of children died from bacterial pneumonia. 17% of adults and 3% of children died from aspiration pneumonia. The proportion of such deaths was greatest in people with severe or profound and multiple learning disabilities. The proportions were similar in 2019 and 2018.

Recommendations specific to pneumonia that were made by reviewers included:

- Improving the training of families, paid carers and professionals about risk factors for aspiration pneumonia and how to alleviate these.
- The need for a national clinical care pathway for people with learning disabilities who have been identified as having a problem with swallowing.
- Attention to postural support, particularly when feeding a person in bed or if they are at risk of vomiting.
- The importance of people receiving the pneumococcal vaccine and the annual influenza vaccine.
- The provision of good oral hygiene and dental care.
- A review of the effects of anti-psychotic medications on people who are prone to chest infections or at risk of aspiration pneumonia.

Deaths from sepsis

Of the deaths notified in 2019, 7% of adults and 7% of children with learning disabilities died from sepsis.
The proportions were similar in 2019 and 2018.

Recommendations specific to sepsis that were made by reviewers included:

- The provision of training for families and paid carers about infection prevention and recognising early signs of sepsis.
- The provision of training for health professionals about the provision of reasonable adjustments.
- The need to adapt the New Early Warning Score 2 to meet the needs of people with learning disabilities.

Deaths from epilepsy

Of the deaths notified in 2019, 6% of adults and 16% of children with learning disabilities died from epilepsy.
A greater proportion of deaths of children were from epilepsy in 2019 than in 2018.

32 completed reviews mentioned Sudden Unexpected Death in Epilepsy (SUDEP). Common themes identified were:

- Observed changes in the person prior to death.
- The use (or absence) of assistive technologies.
- Problems with care related to a person's epilepsy.

Recommendations specific to epilepsy that were made by reviewers included:

- The need for better training about epilepsy for those supporting people with learning disabilities.
- The use of seizure alarms.
- Communication and coordination between primary care and neurology services.
- Timely reviews of medication.
- Local review to ensure that services are following National Institute for Health and Care Excellence (NICE) guidelines.

Deaths from specific urgent or ambulatory sensitive conditions

<u>Deep vein thrombosis or pulmonary embolus (DVT/PE)</u>

145 deaths notified to the LeDeR programme had DVT or PE included in Part I of the MCCD.

Thematic analysis of the circumstances leading to death in the 67 completed reviews identified three key issues:

- The risk factor of reduced mobility.
- Missed signs and symptoms of the person having DVT/PE.
- Problems with the provision of medical care.

Recommendations specific to DVT/PE were:

- The need for risk factors of DVT/PE to be better recognised and reduced, including those of immobility and obesity.
- Additional measures to be put in place for those at high risk of DVT/PE.
- The provision of accessible materials about the risks of DVT/PE and its early identification.
- For NICE Guidelines about preventing DVT/PE to be followed.
- For closer attention to be paid to risks on discharge from hospital.

<u>Diabetes</u>

75 deaths notified to the LeDeR programme had diabetes included in Part I of the MCCD.

Thematic analysis of the circumstances leading to death in the 32 completed reviews identified two key but related issues:

- Assessing mental capacity.
- A prioritisation of the choice of the person.

Recommendations specific to diabetes were:

- Improved staff understanding and adherence to the Mental Capacity Act.
- The appropriate provision of support for people with diabetes, particularly in community settings.

Asthma

51 deaths notified to the LeDeR programme had asthma included in Part I of the MCCD.

Thematic analysis of the circumstances leading to death in the 28 completed reviews identified two key issues:

- Evidence of an increasing number of respiratory problems prior to death.
- Problems accessing healthcare.

There were no recommendations specific to asthma as a cause of death. Most recommendations were general in nature, referring to the provision of learning disability annual health checks, adherence to the Mental Capacity Act, and the need for better communication between those supporting the person.

Influenza

43 deaths notified to the LeDeR programme had influenza included in Part I of the MCCD.

The completed reviews of deaths from influenza highlighted, once again, issues related to:

- Assessing the capacity of a person to make informed decisions about their own care.
- The absence of information in health and care records about reasonable adjustments required.
- How people often missed out on preventative care, including annual health checks and influenza vaccinations.

The only recommendation specific to influenza as a cause of death was in relation to the need for reasonable adjustments to be made for people with learning disabilities when offered influenza vaccinations.

Deaths of people in specific age groups

Children

Overall, 7% of the deaths notified to LeDeR were of children aged 4-17 years. In the general population, just 0.3% of the population die between the ages of 5-19 years.

Of those who died in childhood, 43% were from BAME groups and 46% had profound and multiple learning disabilities.

Over a quarter (27%) of children had an underlying cause of death attributed to disorders of the nervous system (e.g. epilepsy, meningitis).

The most frequently reported issues in relation to the care provided to children and their families were:

- Delays in responding to signs of illness in the child or investigating illness.
- Poor quality multi-disciplinary working.
- Poor advanced care planning.
- Problems with the direct provision of care.

Recommendations specific to children were:

- The need for a key worker to coordinate care and ensure all agencies are involved and informed.
- Planning in relation to advanced care plans and end of life care.

- Better planned and coordinated discharge from hospital.
- Consistent support for and communication with families.

Young people aged 18-24 years

Overall, 4% of the deaths notified to LeDeR were of young people aged 18-24 years. In the general population, just 0.3% of the population die at these ages.

The demographic profile of the young people aged 18-24 was very different to that of adults aged 25 years and over, and more similar to children whose deaths were notified to the programme.

Over a quarter (29%) of those aged 18-24 when they died were from BAME groups and 37% had profound and multiple learning disabilities.

A far greater proportion of young people aged 18-24 years with learning disabilities died from disorders of the nervous system (e.g. epilepsy, meningitis) or respiratory system (e.g. pneumonia) compared to young people in the general population.

Recommendations specific to the 18-24 year old age group were:

- The need for improved communication between children's and adults' services.
- To audit multi-agency involvement in transition planning for children and young people, and to take action accordingly.
- To review processes and documentation for undertaking Mental Capacity Act assessments in young people 16 years and over to ensure they correspond to legislative requirements.
- To improve communication with families.

People aged 75 years and over

Overall, 15% of the deaths notified to LeDeR were of people aged 75 years and over. In the general population, 68% of people die aged 75 years and over.

People with learning disabilities aged 75 years and over were less likely to be from BAME groups (3% compared to 10% of all deaths notified) and more likely to have mild (41%) or moderate (39%) learning disabilities compared to all deaths notified (30% and 34% respectively).

Recommendations specific to the care of people aged 75 and over included:

- Greater attention to forward planning as people age.
- Greater recognition about how a person's experiences at younger ages can impact on their life in later years.
- The provision of training about the physical, psychological and social needs of older people.
- A holistic approach that integrates elderly assessment checks and learning disabilities annual health checks, and results in joint care planning and information sharing.

Summary of recommendations[3]

Recommendation 1. A continued focus on the deaths of all adults and children from BAME groups is required.

Recommendation 2. For the Department of Health and Social Care (DHSC) to work with the Chief Coroner to identify the proportion of deaths of people with learning disabilities (and possibly other protected characteristics) referred to a coroner in England and Wales.

Recommendation 3. (Repeated from the House of Lords Select Committee on the Mental Capacity Act 2005).The standards against which the Care Quality Commission inspects should explicitly incorporate compliance with the Mental Capacity Act as a core requirement that must be met by all health and social care providers.

Recommendation 4. Consider the recommendations from the 'Best practice in care coordination for people with a learning disability and long term conditions'[4] (March 2019) report and:

- Establish and agree a programme of work to implement the recommendations.
- Liaise with NIHR regarding the importance of commissioning a programme of work that develops, pilots and evaluates different models of care coordination for adults and children with learning disabilities.

Recommendation 5. Adapt (and then adopt) the National Early Warning Score 2 regionally, such as the Restore2 in Wessex[5], to ensure it captures baseline and soft signs of acute deterioration in physical health for people with learning disabilities by:

- Involving people with learning disabilities, their families and professional organisations.
- Disseminating for use across acute, primary and community settings.

Recommendation 6. Consider developing, piloting and introducing:

- Specialist physicians for people with learning disabilities who would work within the specialist multi-disciplinary teams.
- A Diploma in Learning Disabilities Medicine
- Making 'learning disabilities' a physician speciality of the Royal College of Physicians.

Recommendation 7. Consider the need for timely, NICE evidence-based guidance that is inclusive of prevention, diagnosis and management of aspiration pneumonia. The outcome of such considerations should be shared with DHSC and NHSE.

Recommendation 8. Right Care to provide a toolkit to support systems to improve outcomes for adults and children at risk of aspiration pneumonia.

Recommendation 9. Safety of people with epilepsy to be prioritised. The forthcoming revision of the NICE Guideline 'Epilepsies in children, young people and adults' to include guidance on the safety of people with epilepsy, and safety measures to be verified in Care Quality Commission inspections.

Recommendation 10. For a national clinical audit of adults and children admitted to hospital for a condition related to chronic constipation. The National Clinical Audit and Patient Outcomes Programme is one way this could happen.

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[3]The recommendations were developed prior to the COVID-19 pandemic. We acknowledge that due to the pandemic, they may not be able to be acted on immediately.

[4]https://ipc.brookes.ac.uk/publications/pdf/Care_coordination_for_people_with_LD_%26_long_term_conditions.pdf

[5]https://wessexahsn.org.uk/projects/329/restore2

Chapter 1

Deaths notified to the LeDeR programme

The LeDeR programme

The LeDeR programme is now established throughout England. A short summary of its development is in Appendix 1.

Those covered by the LeDeR programme

The LeDeR programme reports on deaths of people with learning disabilities[6] aged 4 years and over[7].The definition of 'learning disabilities' as used by LeDeR is 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.'

The review process

The LeDeR review process is described on the LeDeR programme website at www.bristol.ac.uk/sps/leder. A summary of the process is in Appendix 2.

Deaths of children with learning disabilities are reviewed by the statutory Child Death Review programme[8]; completed reviews are shared with the LeDeR programme.

Delivery of the LeDeR programme

The LeDeR programme is delivered by a number of partners, each with different responsibilities. Until 31st May 2020, the University of Bristol has been responsible for:

- The process for being notified about deaths of people with learning disabilities, via a secure web link or a confidential phoneline, and informing relevant local areas about the death.
- Supporting the online LeDeR review system, a secure electronic platform which is used for allocating notifications of deaths to reviewers, monitoring the progress of reviews, and storing review documents and reports.
- Coding, collating and reporting on the findings of completed reviews, through regular themed review reports for NHS England, and the LeDeR programme annual report.

NHS England funds the LeDeR programme. It is responsible for:

- Supporting local agencies and health and care professionals to complete the reviews.
- Using the learning obtained to influence and contribute to service improvements as indicated.

As part of their support to local areas for the timely completion of reviews of deaths, in 2019 NHS England commissioned the North East Commissioning Support Group (NECS) to undertake some reviews of deaths[9].

[6] The terms 'learning disability' and 'learning disabilities' are used interchangeably in this report.
[7] Prior to the age of 4 years it can be difficult to identify if a child has learning disabilities unless they have a specific syndrome associated with learning disabilities.
[8] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/859302/child-death-review-statutory-and-operational-guidance-england.pdf
[9] https://www.necsu.nhs.uk/services/system-wide-transformation/leder/

Deaths notified to the programme

From 1st July 2016 - 31st December 2019, 7,145 deaths were notified to the LeDeR programme (Table 1)[10]. Of these, 516 were children aged 4-17 years and 6,629 were adults.

In 2019, the number of deaths notified was 3,060.

This is a slightly smaller number than that estimated by Public Health England in 2017[11], which was of approximately 3,400 deaths of people with learning disabilities in England each year.

Table 1: Number of in-scope notifications of deaths of people with learning disabilities aged 4 years and over, by NHS England region

	1st July – 31st Dec. 2016	1st Jan. – 31st Dec. 2017	1st Jan. – 31st Dec. 2018	1st Jan. – 31st Dec. 2019	Total
North West	10	236	380	436	1,062
North East & Yorkshire	46	327	392	537	1,302
Midlands	*	128	534	621	1,284
East of England	0	137	338	345	820
South East	25	132	521	477	1,155
London	*	180	312	338	834
South West	14	125	243	306	688
Total♦	100	1,265	2,720	3,060	7,145

* Number of deaths fewer than 10.

♦Notifications between 2016 and 2018 are slightly lower than reported last year, as 216 notifications have since been identified as duplicates and removed from the data.

Progress in completing reviews

Of the 7,145 deaths that have been notified to the LeDeR programme, the reviews have been completed for 3,195 (45%). Of these completed reviews, 246 were children and 2,949 were adults.

Figure 1 shows the number of notifications and completed reviews each quarter since the start of the LeDeR programme.

As the chart shows, the number of deaths notified each quarter has been consistently in excess of the number of reviews completed, although there was a marked reduction in the gap from October – December 2018 which appears to have been subsequently sustained.

[10] For ease of reading, data tables are not included here but are available from Pauline.Heslop@bristol.ac.uk on request.
[11] In our last annual report, we noted that people with learning disabilities are unlikely to be evenly distributed across England due to historic patterns of institutional care.

Figure 1: The number of notifications and the number of completed reviews each quarter since the start of the LeDeR programme

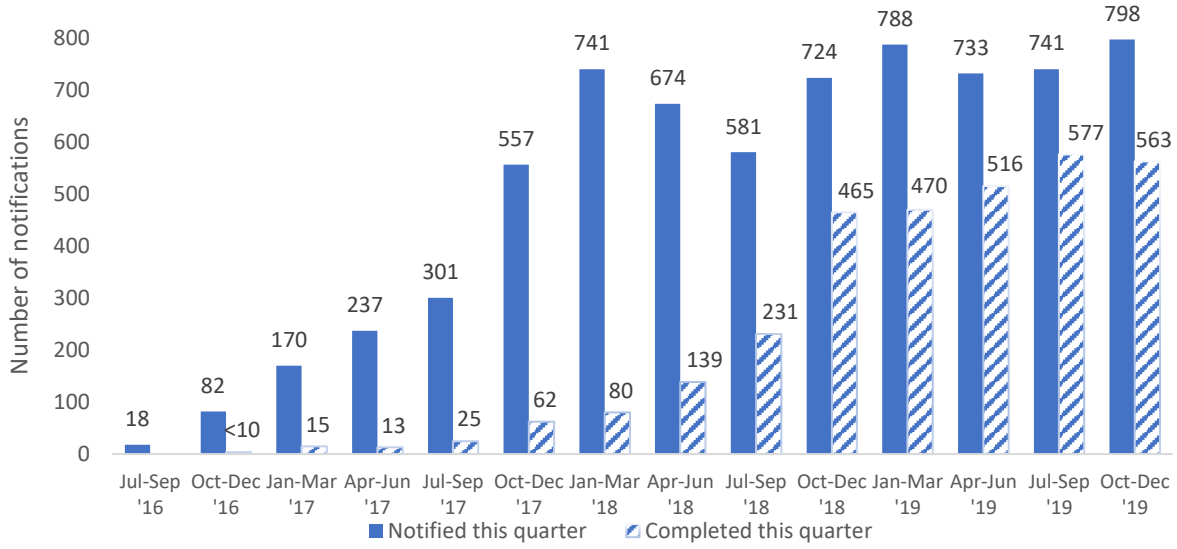
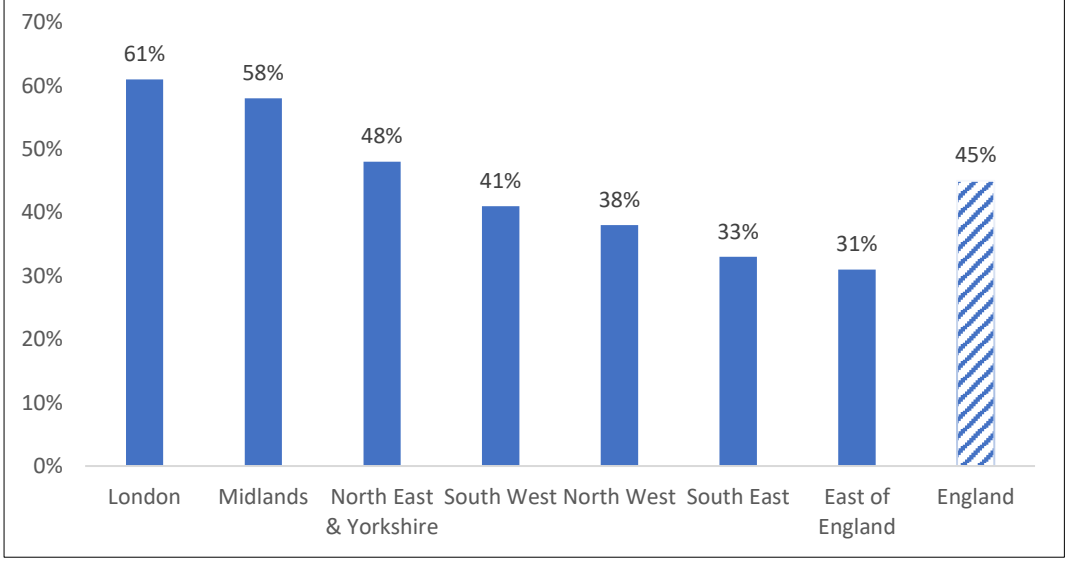


Figure 2 shows the proportion of completed reviews by region[12]. London had the largest proportion of completed reviews (61%); the East of England the least (31%). A map showing the geographical distribution of completed reviews by CCG is in Appendix 4.

Figure 2: The proportion of completed reviews, by region, to 31st December 2019



[12] Appendix 3 provides more detail about the notification of deaths and progress of reviews to 31st December 2019, by time period and by region.

Initial reviews and multi-agency reviews

As already mentioned, all deaths of children aged 4-17 years receive a statutory child death review.

All deaths of adults with learning disabilities receive a LeDeR initial review. The purpose of this is to provide sufficient information to be able to determine if there are any areas of concern in relation to the care of the person who has died.

If areas of significant concern have been raised, or if any further learning could be gained from a multi-agency review of the death that would contribute to improving practice, a LeDeR multi-agency review should be undertaken. In some local areas, these have been in conjunction with other safeguarding or serious incident investigations.

Prior to 2019, some deaths of people from Black, Asian and Minority Ethnic (BAME) groups and young people aged 18-24 years would also have automatically received a multi-agency review as part of the LeDeR programme focus on these groups[13].

Of the 2,949 deaths of adults for whom a review has been completed since the inception of LeDeR, 7% (n=209) have received a LeDeR multi-agency review.

The proportion of completed reviews that received a LeDeR multi-agency review in 2019 was 6% (n=117).

A thematic analysis of the key issues raised in multi-agency reviews is in Chapter 4. Recommendations made by multi-agency reviews are included in Appendix 6.

[13] More information about this can be found in the third LeDeR annual report (2018).

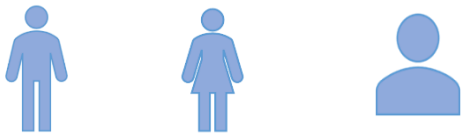
Chapter 2

The people with learning disabilities included in this report

In this chapter we focus on the 7,145 people with learning disabilities whose deaths were notified to the LeDeR programme between 1st July 2016 and 31st December 2019[14].

Gender

The person's gender was reported for 7,127 deaths. Of these, over half (58%) were males.



4,104 males (58%) | 3,023 females (42%) | 18 missing or 'other' gender (0.3%)

Ethnicity

The person's ethnicity was reported for 6,569 deaths. The majority (90%) were of white British ethnicity; 4% were Asian; 2% from other white ethnic groups; 2% mixed and 2% were from other ethnicities[15].

The proportion whose ethnic group was described as 'white British' was higher at 90% than the 86% recorded for England and Wales in 2018[16].

Level of learning disabilities

The level of a person's learning disabilities was reported for 3,557 deaths. Of these, 30% were known to have had mild learning disabilities; 33% had moderate learning disabilities; 27% severe learning disabilities; and 10% profound and multiple learning disabilities.

How personal characteristics interact

People from BAME groups died at disproportionately younger ages than white British people. Of those who died in childhood, 43% were from BAME groups (Figure 3).

There are two potential explanations for this:

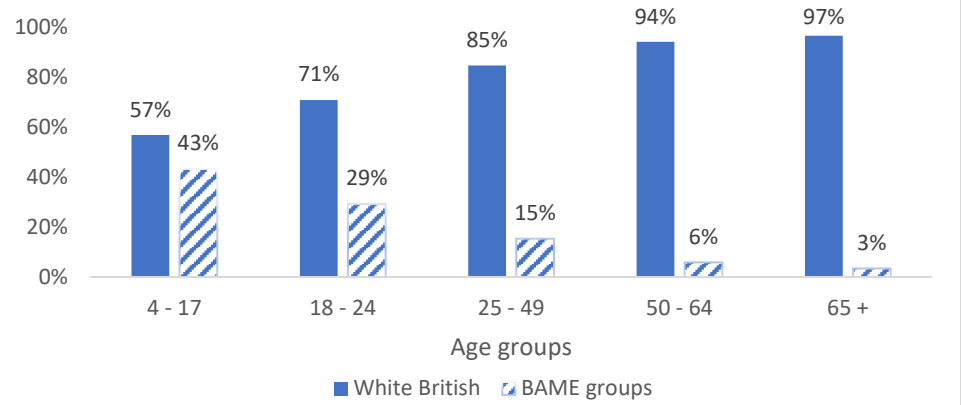
1. That people from BAME groups die at younger ages than white British people.
2. There could be a reporting bias in the data if deaths of adults from BAME groups are under-reported to the LeDeR programme, which we are unable to ascertain.

[14] At the point of notification of a death, some of the key demographic information may be missing; the reviewer would complete any missing information during the review process. We have excluded missing data from the information presented.

[15] The number of deaths of people from different Black and Minority ethnic groups is too small for analysis by individual ethnicities. They have therefore been merged into a 'non-White British grouping' which refers to anyone who is not of a white British ethnicity.

[16] https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/national-and-regional-populations/population-of-england-and-wales/latest

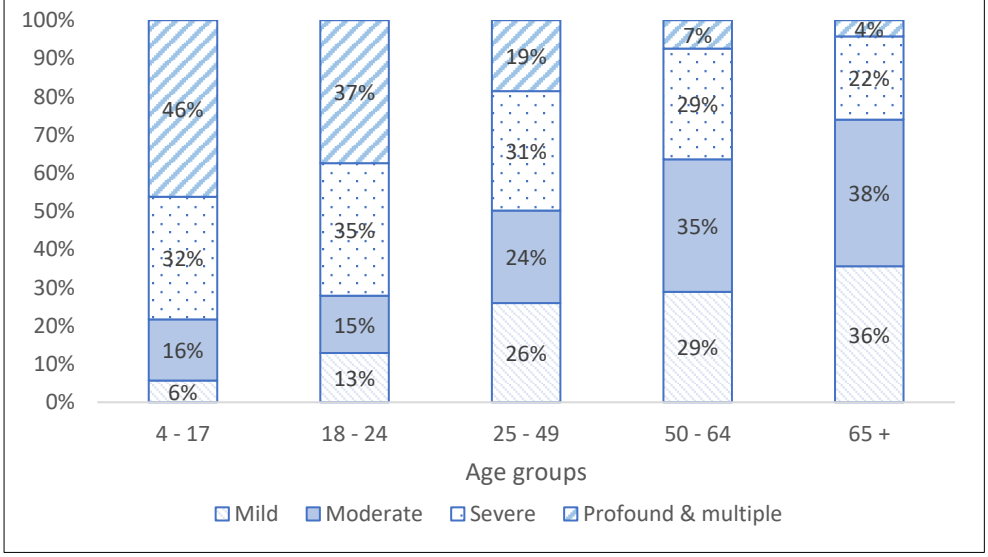
Figure 3: The proportion of deceased people in different age groups, by ethnic group



As we mentioned in previous annual reports, people with profound and multiple learning disabilities disproportionately died at younger ages; some would have had complex medical conditions or genetic conditions that may make an earlier death likely.

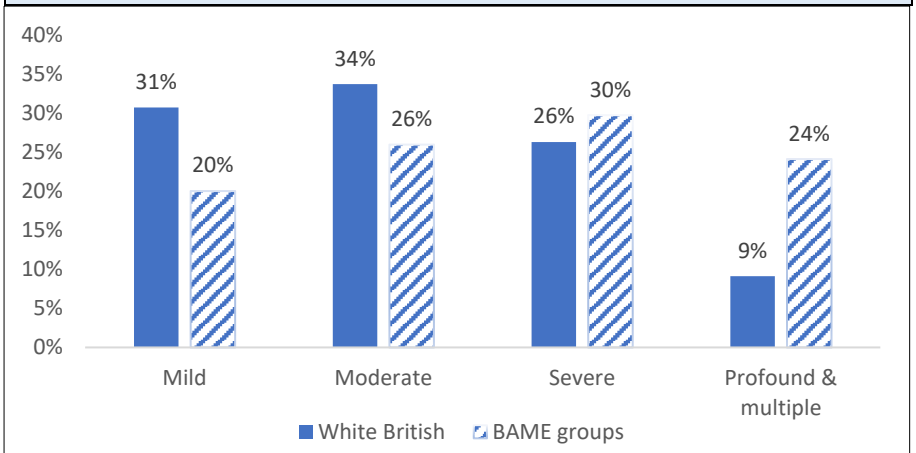
Of the people who died in childhood, 46% had profound and multiple learning disabilities (Figure 4).

Figure 4: The proportion of deceased people in different age groups, by level of learning disabilities



People from BAME groups were over-represented in those with severe or profound and multiple learning disabilities. A quarter (24%) of people from BAME groups had profound and multiple learning disabilities, whereas this was the case for 9% of people from white British ethnicity (Figure 5).

Figure 5: The proportion of deceased people with different levels of learning disability, by ethnicity



Multimorbidity

Multimorbidity is defined as the presence of two or more long-term health conditions[17]. Long-term health conditions are those that cannot be cured but can be controlled with ongoing management (using medication and/or other therapies) over a period of years.

Of 3,195 people with learning disabilities whose deaths have been reviewed, 3,006 (94%) had at least one long-term health condition. The mean number of long-term health conditions was three.

The five most common long-term health conditions reported in completed reviews were:

- Epilepsy (36%).
- Cardiovascular problems (32%).
- Dysphagia (29%).
- Mental ill health (26%).
- Constipation (23%).

The most common combinations of two long-term health conditions were:

- Epilepsy and dysphagia (14%).
- Epilepsy and cardiovascular problems (10%).
- Cardiovascular problems and dysphagia (10%).

The most common combinations of three long-term health conditions were:

- Epilepsy and dysphagia and dementia (5%).
- Epilepsy and dysphagia and constipation (4%).
- Epilepsy and cardiovascular problems and dysphagia (4%).

There was a weak association between the level of a person's learning disabilities and the number of long-term conditions they had. People with mild learning disabilities had an average (mean) number of 3.2 long-term conditions; for people with moderate learning disabilities it was 3.1; for severe learning disabilities it was

[17] https://www.nice.org.uk/guidance/ng56

3.0; and for profound and multiple learning disabilities it was 2.6. This is perhaps reflective of people with profound and multiple learning disabilities dying disproportionately at younger ages which would reduce the chance for some long-term conditions to develop.

There was also an association between ethnicity and the number of long-term conditions. People of white British ethnicity had an average (mean) of 3.0 long-term health conditions; people from BAME groups had an average (mean) of 2.4 long-term conditions. This is probably reflective of people from BAME groups being over-represented in those with severe or profound and multiple learning disabilities.

Somewhat surprisingly, there was little association between the presence of multimorbidity and median age at death for males or females (Table 2).

Table 2: Median age at death for people with learning disabilities and long-term health conditions

Males	**Number**	**%**	**Median age at death**
No long-term health condition	123	7%	55
One long-term health condition	290	16%	56
Two long-term health conditions	396	21%	57
Three or more long-term health conditions	1,038	56%	61
Females			
No long-term health condition	66	5%	54
One long-term health condition	213	16%	53
Two long-term health conditions	293	22%	61
Three or more long-term health conditions	772	57%	58

Medication use

Information about medication was available from 2,387 completed reviews of adults with learning disabilities whose deaths were reviewed in 2019.

Number of medications prescribed

Most (97%) had had one or more medications prescribed (Table 3). The mean (average) number of prescribed medications was 5.8 (range 0 – 21). There was little difference in the mean number of medications prescribed by gender, ethnicity or level of learning disabilities[18].

Table 3: The number of medications prescribed

Number of medications	**People prescribed this number (No.)**	**People prescribed this number (%)**
0	62	3%
1	115	5%
2	211	9%
3	232	10%
4	289	12%
5	275	11%
6	300	13%
7	251	10%
8	170	7%
9	149	6%
10	106	4%
11 or more	227	10%
Total	2,387	100%

[18] Comparable data for the general population is not available.

Most commonly prescribed usual medication

Table 4 shows the names of the most commonly prescribed usual medications and the number of people prescribed them. Almost a quarter (22%) of people had been prescribed Sodium Valproate, a drug given to treat epilepsy or bipolar disorder.

Table 4: The names of the most commonly prescribed usual medications and the number of people prescribed

Name of medication	People prescribed this (No.)	People prescribed this (%)
Sodium Valproate	531	22
Lansoprazole	455	19
Omeprazole	419	18
Levothyroxine	395	17
Paracetamol	391	17
Levetiracetam	309	13
Carbamazepine	297	12

The most commonly prescribed medications differed according to personal characteristics.

Females were more commonly prescribed Levothyroxine than males. People from BAME groups were more commonly prescribed Levetiracetam than white British people. People with mild learning disabilities were least commonly prescribed Sodium Valproate; those with profound and multiple learning disabilities were more commonly prescribed Levetiracetam. Azithromycin was commonly prescribed in children, and Baclofen was commonly prescribed in those aged 18-24 years old.

Most commonly prescribed categories of medications

Table 5 shows the most commonly prescribed categories of medicines.

Table 5: Categories of medication most commonly prescribed

Category of medication	People prescribed this (No.)	People prescribed this (%)
Gastrointestinal system		
Proton Pump Inhibitors (reduce stomach acid production)	983	42
Laxatives	774	33
Neurological system		
Antiepileptics	871	37
Antidepressants	630	27
Antipsychotics	559	23
Analgesics	454	19
Hypnotics	175	7
Cardiovascular system		
Anti-hypertensives and treatments for heart failure	485	20
Lipid regulating drugs	463	20
Respiratory system		
Bronchodilators	148	6

The most commonly prescribed category of medication was that of Proton Pump Inhibitors which reduce stomach acid production. Four in ten (42%) of people with learning disabilities were prescribed these medications, the proportion rising to 50% of those with profound and multiple learning disabilities.

The next most commonly prescribed category of medications was antiepileptics

– prescribed for 37% of people with learning disabilities. We have already seen that epilepsy with the most common long-term health conditions reported for 36% of people with learning disabilities.

A third of people (33%) were prescribed laxatives to treat constipation.

Antidepressants were prescribed for just over a quarter (27%) overall, more so for people with mild learning disabilities (36%) and those aged 65 years and over (30%).

Drugs to treat hypertension and heart failure (health conditions usually associated with older age) were prescribed to a fifth (20%) of people with learning disabilities overall; more so to people with mild learning disabilities (33%) and to those aged 65 years and over (28%).

A similar pattern, as might be expected, was found for lipid-regulating drugs. These were prescribed for 20% of people with learning disabilities overall, but more so to people with mild learning disabilities (30%) and to those aged 65 years and over (30%).

Antipsychotic medications

Antipsychotics are one type of psychotropic medication used to treat a number of conditions, including, bipolar disorder, schizophrenia and psychosis; sometimes they are prescribed to help manage behaviour.

There is a concern that people with learning disabilities are prescribed antipsychotic medication although they may not have the health conditions for which the medicines are prescribed[19]. Since 2015, NHS England has been supporting actions to tackle the over-prescribing of psychotropic drugs in general, including antipsychotics, for people with learning disabilities through the STOMP/STAMP programme[20].

Almost a quarter (23%) of the people whose deaths were reviewed by the LeDeR programme were usually prescribed an antipsychotic medication. The proportion was greatest for people with mild learning disabilities (28%) and people aged 65 years and over (28%).

Table 6 shows the four most frequently prescribed antipsychotic medications.

Table 6: The most frequently prescribed antipsychotic medication

Name of antipsychotic medication	People prescribed this (No.)	People prescribed this (%)
Risperidone	180	8
Olanzapine	104	4
Quetiapine	66	3
Chlorprom-azine	64	3

Published prescribing guidelines such as those developed by National Institute for Clinical Excellence (NICE), suggest that people with a psychotic illness should only receive one antipsychotic at a time. Most of those prescribed antipsychotic medication were taking one type of antipsychotic medication, but 49 people (8% of those prescribed antipsychotics) were taking two or more.

[19] https://webarchive.nationalarchives.gov.uk/20160704150153/http://www.improvinghealthandlives.org.uk/publications/1248/Prescribing_of_psychotropic_medication_for_people_with_learning_disabilities_and_autism

[20] https://www.england.nhs.uk/2015/07/urgent-pledge/

Potential drug interactions

We analysed whether any of the medications prescribed to a person were known to interact with each other in potentially adverse ways, using guidelines issued by NICE and the British National Formulary[21]. Care must be taken in interpreting this, as they are potential interactions, not adverse interactions, based on the information that has been supplied in completed reviews. Such potential interactions are classed as 'severe', 'moderate' or 'unstated' and based on sources of evidence including studies, theory or anecdotal reporting. In what follows, we only include those interactions which were supported in studies.

Potentially severe interactions may result in a life-threatening event or have a permanent detrimental effect. These were identified in 238 (12%) of the completed reviews of adults in 2019. The most common potentially severe interaction was in relation to Sodium Valproate, with Lamotrigine, Topiramate and Phenytoin. Another common potentially severe interaction was between Citalopram and Omeprazole.

Potentially moderate interactions can cause considerable distress or partially incapacitate a patient; they are unlikely to be life-threatening or result in long-term effects. These were identified in 375 (19%) of the completed reviews of adults in 2019. The most common potentially moderate interactions were in relation to Carbamazepine, with Midazolam, Levothyroxine and Olanzapine. Another common potentially moderate interaction was between Paracetamol and Phenytoin.

[21] https://bnf.nice.org.uk/interaction/

Chapter 3

The deaths of people with learning disabilities

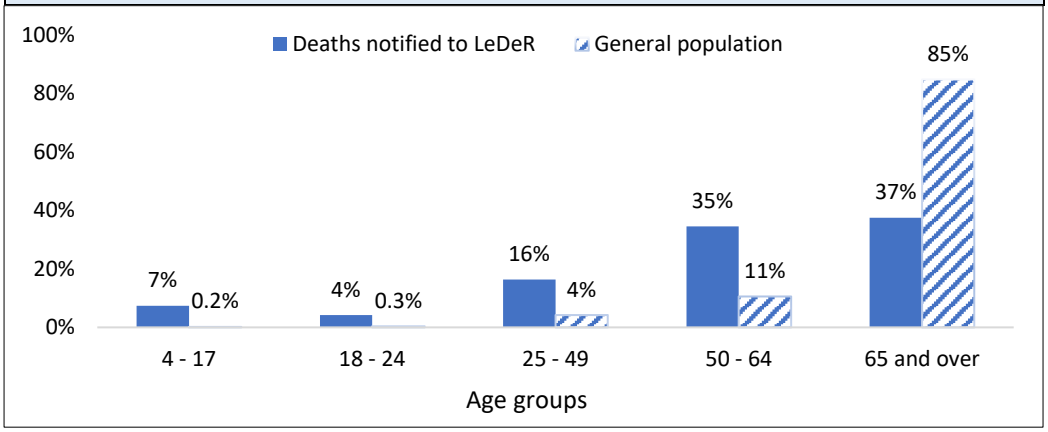
Age at death

In this section we report on the age at death of people with learning disabilities who died from 1st April 2017 onwards[22]. Comparisons with the general population are indicative but not directly comparable: deaths of people with learning disabilities are notified from the age of four years, while general population data also include information about children aged 0-3 years.

Age group at death

Figure 6 shows the age group at death of those people with learning disabilities who died from 1st April 2017 onwards, compared to general population data for the UK for 2018[23]. In 2018, the majority (85%) of people in the UK population died aged 65 and over. The corresponding proportion of people with learning disabilities was 37%.

Figure 6: Age group at death, people with learning disabilities and the general population



The median age at death[24]

The median age at death for 7,145 people with learning disabilities (aged 4 years and over) was 60 years. For males it was 60 years (min 4 years; max 98 years); for females it was 59 years (min 4 years; max 104 years) (Figure 7).

For deaths notified in 2019, the median age at death was 61 for males and 59 for females, thus there is an increase of one year for males since 2018.

In the general population of England from 2016- 2018, the median age at death (for people of all ages, including 0-4 years) was 83 years for males and 86 years for females[25]

Our updated data suggests that the disparity between the age at death for

[22] From 2016 to 31st March 2017 the LeDeR programme only reviewed the deaths of people aged 74 or less. The upper age limit was then removed to align the LeDeR programme with the Learning from Deaths national framework. Here, we only report on deaths from 1st April 2017 onwards, in order to aid comparisons with national data and ensure consistent interpretation of the data.

[23] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathregistrationssummarytablesenglandandwalesdeathsbysingleyearofagetables

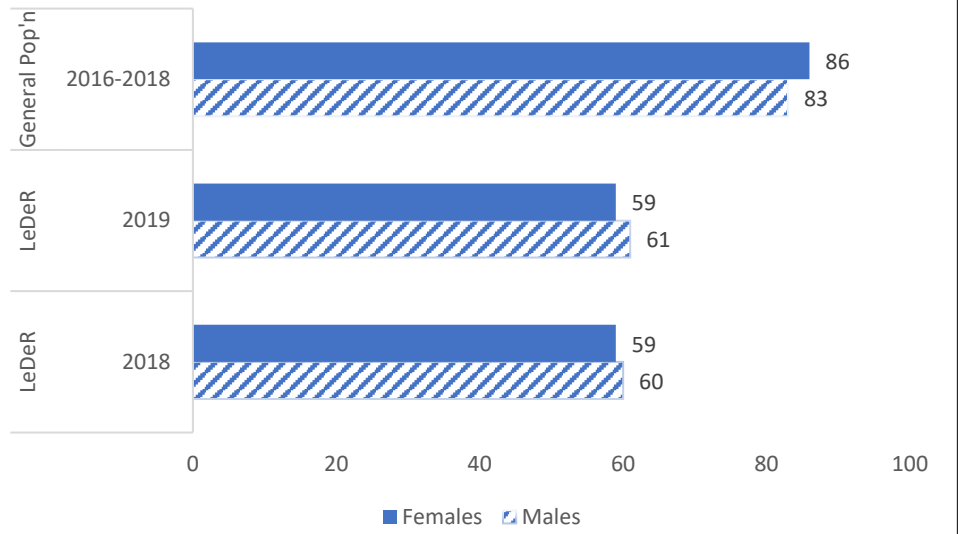
[24] The median age at death is the age at which exactly half the deaths were deaths of people above that age and half were deaths below that age.

[25] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/datasets/averageageatdeathbysexuk

people with learning disabilities (age 4 years and over) and the general population (all ages) in 2019 was 22 years for males and 27 years for females.

There is a reduction of one year in the disparity between the age at death of men with learning disabilities compared with men in the general population.

Figure 7: The median age at death for males and females with learning disabilities notified to the LeDeR programme in 2019 and 2018, and the general population 2016-2018



The median age at death varied slightly by geographical region as Table 7 shows - it was highest for males in the South West, and for females in the South West and London.

Table 7: The median age at death by gender and region

(Deaths from 1st April 2017)	**Males**	**Females**	**All**
North West	60	58	59
North East & Yorkshire	59	59	59
Midlands	60	59	59
East of England	62	58	61
South East	61	59	60
London	58	60	59
South West	63	60	61
All	60	59	60

In our last annual report, we noted that there was considerable variation in the median age at death according to the level of a person's learning disabilities, and their ethnicity.

People with severe or profound and multiple learning disabilities had a lower median age at death than those with mild or moderate learning disabilities; people from BAME ethnic groups had a lower median age at death than white British people.

Table 8 shows the updated information for the median age at death of all deaths 1st April 2017 to 31st December 2019.

Table 8: Median age at death by ethnicity and level of learning disabilities			
Level of learning disabilities	**Ethnic group**	**Median age at death 1st April 2017 – 31st Dec 2019**	**Number**
Mild / moderate	White British	64	1,915
Mild / moderate	BAME	54	139
Severe / profound & multiple	White British	57	1,044
Severe / profound & multiple	BAME	31	163

We considered whether the median age at death was influenced by the cause of death, particularly people with Down's syndrome who develop early onset Alzheimer's disease. This appeared not to be the case.

Table 9: Median age at death by cause of death (as recorded on Pt I of MCCD)	
(Deaths from 1st April 2017 and where ICD-10 codes are available)	**Median age at death**
Bacterial pneumonia	61
Sepsis	61
Aspiration pneumonia	60
Down's syndrome and dementia/Alzheimer's disease	60
Epilepsy	50

Table 9 shows that the median age at death for people with Down's syndrome and dementia/Alzheimer's disease was 60, whereas the median age at death for people from epilepsy, for example, was 50 years.

Month of death

Of 7,096 deaths for which date of death was reported, the peak months of deaths were October to December. There was a greater proportion of deaths of people with learning disabilities from October – December than in the general population[26] (Figure 8).

Place of death

Of the 6,931 notifications of deaths of people with learning disabilities for which the place of death was reported, 60% died in hospital.

When considering only those whose deaths were reviewed in 2019, the proportion was 60%, a slightly smaller proportion than the 62% reported in our last annual report.

In England in 2018, just under a half (46%)[27] of deaths of all ages occurred in hospital, a considerably smaller proportion than that of people with learning disabilities (Figure 9).

[26] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/monthlyfiguresondeathsregisteredbyareaofusualresidence

[27] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables

Figure 8: Month of death: people in the general population (2019) and deaths notified to LeDeR

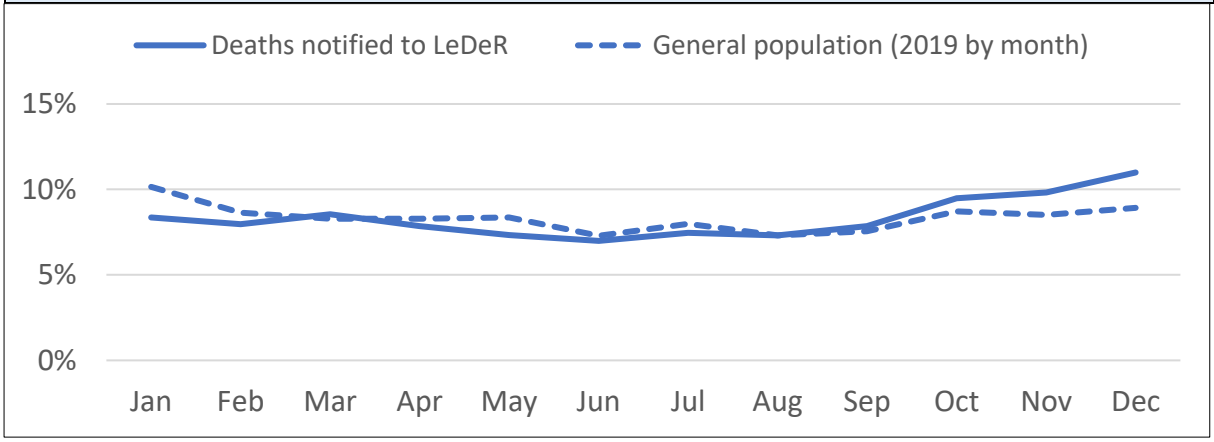
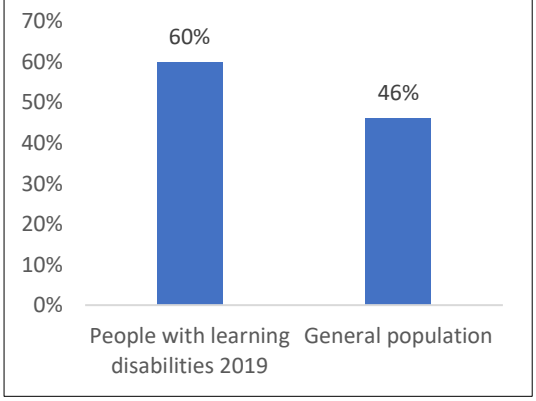


Figure 9: Proportion of deaths in hospital for people with learning disabilities and the general population



Whether a person with learning disabilities died in hospital was related to their ethnicity and level of learning disabilities: 66% of deaths of people from BAME groups occurred in hospital; 69% of deaths of people with profound and multiple learning disabilities.

Deaths of people in contact with specialist mental health services

Of the deaths reviewed in 2019, 14 people had previously been an inpatient at an Assessment and Treatment Unit (learning disabilities), or a specialist hospital (mental health) where they had been held under a section of the Mental Health Act, sometimes many years prior to their death.

Nine people were either a current inpatient at the time they died or had been discharged less than two months prior to their death. Reviewers had graded the care for fewer than five of the nine as meeting good practice. Fewer than five deaths were felt to have received care that fell short of expected good practice in one or more significant areas, but which did not significantly impact on the person's well-being. Fewer than five people were felt to have received care that fell so far short of expected good practice that it contributed to the cause of their death.

Issues identified in these deaths included a lack of attention to physical health issues, poor care coordination, a lack of

holistic care provision, and a lack of supervision or observation.

> "Physical health needs appear not to have been adequately monitored despite known risks associated with several long-term conditions." (reviewer).

Deaths of people in contact with the criminal justice system

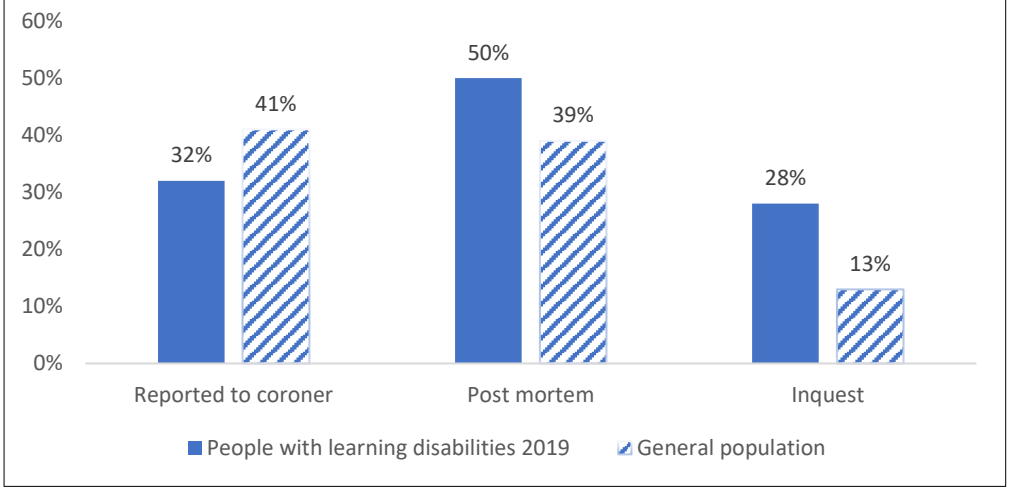
Of the deaths reviewed in 2019, 15 people had previously been incarcerated in prison, often many years before their death. Many had been convicted for drug or alcohol abuse or assault.

Fewer than five people were in prison at the time of their death. To protect anonymity, further analysis of these deaths is not presented here.

Deaths reported to a coroner

Of the 1,946 deaths of adults with learning disabilities for which a review was completed in 2019, 32% were known to have been reported to a coroner, a substantially smaller proportion than the 41% of adults and children in the general population who died in 2018[28] (Figure 10). It was a similar proportion than the 31% of deaths of people with learning disabilities reviewed in 2018.

Figure 10: Deaths reported to a coroner, adults with learning disabilities (2019) and general population (adults and children) (2018)



Post-mortem examinations were carried out on 50% of the deaths of adults with learning disabilities reported to a coroner, a considerably greater proportion than people in the general population in 2018 (39%), and a greater proportion than those people with learning disabilities whose deaths were reviewed in 2018 (46%).

Coroners inquests were opened for 28% of deaths of adults with learning

[28] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/810303/Coroners_Statistics_Annual_2018.pdf

disabilities reported to a coroner, a considerably greater proportion than people in the general population in 2018 (13%), and a greater proportion than those people with learning disabilities whose deaths were reviewed in 2018 (14%).

Whether or not the death of a person with learning disabilities had been reported to a coroner was related to a person's age, ethnicity and level of learning disabilities.

- Those aged 18-24 years of age more frequently had their deaths reported to a coroner (40%) than people aged 65 and over (26%).
- Adults from BAME ethnic groups more frequently had their deaths reported to a coroner (39%) than white British people (31%).
- Adults with mild learning disabilities more frequently had their deaths reported to a coroner (37%) than those with moderate (27%), severe (30%) or profound and multiple (29%) learning disabilities.

Deaths with a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision[29] or a decision to allow a natural death

Of 1,875 deaths of adults reviewed in 2019 for whom data was available about DNACPR decision, 72% had such a decision. Reviewers felt that the majority of these (78%) were appropriate, correctly completed and followed.

Whether or not a person had a DNACPR decision varied by their age group, ethnicity and the level of a person's learning disabilities.

- People aged 65 and over were more frequently reported to have a DNACPR decision (78%) than young adults aged 18-24 years old (59%).
- White British people more frequently had DNACPR decisions (74%) than people from BAME groups (60%).
- People with severe (78%) or profound and multiple learning disabilities (77%) more frequently had a DNACPR decision than people with mild (65%) or moderate (74%) learning disabilities.

There were no instances reported of cardiopulmonary resuscitation (CPR) inappropriately being denied; there was one report of CPR being attempted although a decision not to attempt CPR had previously been documented.

We reported in our 2018 annual report that 19 reviewers noted the inappropriate inclusion of 'learning disabilities' or a related condition as a reason for a DNACPR decision[30].

Of the reviews of deaths completed in 2019, 13 reviews noted that 'learning disabilities' had been included as a reason for not resuscitating the person. Eleven of the 13 people had died before the 20th May 2019 when Professor Stephen Powis,

[29]Cardio-pulmonary resuscitation is when a person receives chest compressions and artificial breaths to help pump blood around their body when their heart has stopped. A decision not to attempt cardio-pulmonary resuscitation is made and recorded in advance when it would not be in the best interests of the person because they are near the end of their life or the procedure would be unlikely to be successful.

[30]Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing explicitly states that decisions about DNACPR must not be based on assumptions related to the person's age, disability or the professional's subjective view of a person's quality of life. https://www.resus.org.uk/dnacpr/decisions-relating-to-cpr/

national Medical Director, sent a letter to senior clinicians reminding them that the terms 'learning disability' and 'Down's syndrome' should never be a reason for issuing a DNACPR decision. One death occurred 13 days after the letter was issued; the other was a month afterwards.

Some of DNACPR decisions that had originally included the terms 'learning disability' or 'Down's syndrome' had been challenged and subsequently changed.

> "The original DNACPR form stated learning difficulties as the reason why CPR might prove unsuccessful. This was changed to 'frailty' following a review by the GP." (reviewer).

> "DNACPR had to be completed twice as initial DNACPR reason given not to resuscitate was Downs Syndrome which was not appropriate. The learning disability speciality nurse spotted this and requested for it to be changed." (reviewer).

Several reviewers noted some dissatisfaction with timing of, or the way in which the DNACPR decision had been made. One reviewer, for example, reported that the person's sister had been upset about a DNACPR decision being discussed before a definitive diagnosis was made. Other reviewers noted that although the documentation appeared to have been correctly completed and followed, there was upset about the manner in which a discussion was held or confusion by the family about the content of the discussion.

One family member commented that they hadn't understood "what constitutes conservative treatment"; another reviewer noted that "the process could have explained better in terms of the context i.e. informing (a person's father) that there was a high risk that his son may die."

> "Her sister told me that she was very distressed by the manner and attitude of the doctor who informed her that Fiona would not be for resuscitation in the event of a respiratory or cardiac arrest by telephone. His manner was curt unfeeling and abrupt. Her sister felt that it was obvious that the decision had already been made." (reviewer).

Causes of death

Concerns have continued about the accuracy of the coding of causes of death on Medical Certificates of Cause of Death (MCCD)[31] of people with learning disabilities nationally and internationally, particularly in relation to listing learning disabilities or an associated condition as an underlying cause of death[32].

Underlying cause of death by ICD-10 chapter

The World Health Organisation defines the underlying cause of death as the

[31] MCCD are divided into two sections, Parts I and II. Part I contains the immediate cause of death, tracking the sequence of causes back to any underlying cause or causes. Part II is used to list other significant conditions, diseases or injuries that contributed to the death, but were not part of the direct sequence. Guidance for doctors completing MCCD in England and Wales is available at: https://www.gov.uk/government/ publications/guidance-notes-for-completing-a-medical-certificate-of-cause-of-death

[32] To listen to a recording of a webinar about the coding of causes of death in people with learning disabilities, go to: http://www.bristol.ac.uk/sps/leder/news/coding-causes-of-deaths-webinar.html

disease or injury which initiated the train of events leading directly to death, or the circumstances of the accident or violence which produced a fatal injury.

Here we present underlying cause of death data for the 5,996 deaths notified to the LeDeR programme before 31st December 2019, for which we have received the official Office for National Statistics ICD-10 codes via NHS Digital for the causes of death[33].

Table 10 indicates, by ICD-10 chapter, the most frequently reported underlying causes of death in people with learning disabilities by gender, age group, ethnicity and level of learning disabilities.

As Table 10 shows, the most frequently reported underlying cause of death was in the ICD-10 chapter of disorders of the respiratory system: 20% of males and 19% of females died from these causes. The proportion varied by age – with the highest proportion (26%) being in people aged 65 and over.

In the general population, deaths from disorders of the respiratory system were the third most frequently reported category of underlying cause of death, affecting 14% of males and 14% of females.

The second most frequently reported underlying cause of death in people with learning disabilities was in the ICD-10 chapter of disorders of the circulatory system: 15% of males and 14% of females died from these causes. The proportion varied by age – with the highest proportion (19%) being in people aged 65 and over. It also varied by level of learning disabilities, the highest proportions being in people with moderate (20%) or severe (19%) learning disabilities.

In the general population, deaths from disorders of the circulatory system was also the second most frequently reported category of underlying cause of death, affecting 26% of males and 23% of females.

The third most frequently reported underlying cause of death in people with learning disabilities was in the ICD-10 chapter of congenital and chromosomal disorders: 15% of males and 14% of females died from these causes. The proportion varied by age – with the highest proportion (23%) being in people aged 50-64 years. It also varied by level of learning disabilities, the highest proportion (19%) being in people with mild learning disabilities.

Congenital and chromosomal disorders was reported as the underlying cause of death in less than 1% of the general population.

[33]In England and Wales, completed Medical Certificates of Cause of Death (MCCD) are coded by the Office for National Statistics (ONS) according to the International Classification of Diseases (version 10) (ICD-10). In order to ensure we have accurate coding for the deaths of people with learning disabilities, we receive the official ONS ICD-10 codes via NHS Digital for the causes of death of people with learning disabilities whose deaths have been notified to LeDeR. We refer to these deaths as 'notified deaths for which we have cause of death data'.

Table 10: The most frequently reported underlying causes of death, by ICD-10 chapter, in people with learning disabilities by gender, age group, ethnicity and level of learning disabilities

	General population[34]		People with learning disabilities												
	Male all ages %	Female all ages %	Male age 4+ %	Female age 4+ %	Age 4 -17 %	Age 18-24 %	Age 25-49 %	Age 50-64 %	Age 65+ %	White British	BAME groups	Mild LD	Mod'te LD	Severe LD	Prof/ multip-le LD
Respiratory system	14%	14%	20%	19%	16%	18%	19%	15%	26%	20%	19%	18%	19%	23%	24%
Circulatory system	26%	23%	15%	14%	4%	7%	11%	15%	19%	15%	12%	7%	20%	19%	9%
Congenital and chromosomal	0.2%	0.2%	14%	15%	13%	14%	13%	23%	7%	15%	10%	19%	17%	11%	5%
Neoplasms	30%	26%	13%	15%	5%	5%	13%	17%	15%	15%	11%	22%	14%	8%	6%
Nervous system	6%	7%	14%	12%	27%	33%	21%	11%	7%	12%	21%	7%	10%	16%	30%
Digestive system	5%	5%	7%	7%	4%	7%	7%	7%	7%	7%	7%	8%	6%	7%	9%
Mental behavioural & neuro-developmental	7%	12%	4%	5%	*	*	3%	3%	8%	5%	2%	3%	6%	6%	4%
Endocrine, nutritional and metabolic	2%	2%	3%	3%	12%	5%	4%	2%	2%	2%	7%	3%	2%	2%	3%
External causes	6%	3%	3%	2%	4%	*	3%	3%	2%	2%	3%	3%	2%	3%	3%
Genitourinary	1%	2%	3%	3%	*	*	2%	2%	3%	3%	*	3%	2%	2%	3%
Infections	1%	1%	2%	2%	8%	*	2%	1%	2%	2%	3%	2%	2%	1%	*
All other causes	2%	5%	2%	3%	5%	3%	3%	2%	3%	3%	3%	4%	1%	2%	2%
Total number	**266,305**	**272,334**	**3,444**	**2,539**	**368**	**221**	**894**	**1,958**	**2,159**	**5,034**	**516**	**978**	**1,115**	**888**	**355**

[34] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables

Most commonly reported condition-specific underlying causes of death

The most commonly reported condition-specific underlying causes of death vary by gender and age group.

Table 11 contrasts these for the general population and people with learning disabilities, by age group.

Table 11: Leading underlying causes of death (with ICD-10 codes) by age group and gender

Age group	People with learning disabilities (deaths notified to LeDeR in 2018 and 2019)	General population[35] (deaths registered in 2018)
Males		
5-19	Cerebral palsy (G80)	Suicide and injury/poisoning undetermined intent (X60 – X84)
20-34	Cerebral palsy (G80)	Suicide and injury/poisoning undetermined intent (X60 – X84)
35-49	Bacterial pneumonia (J12 – J18)	Accidental poisoning (X40 – X49)
50-64	Down's syndrome (Q90)	Ischaemic heart diseases (I20 – I25)
65-79	Bacterial pneumonia (J12 – J18)	Ischaemic heart diseases (I20 – I25)
80+	Bacterial pneumonia (J12 – J18)	Dementia & Alzheimer's disease (F01-F03, G30)
All males	*Down's syndrome (Q90)*	*Ischaemic heart diseases (I20 – I25)*
Females		
5-19	Cerebral palsy (G80)	Suicide and injury/poisoning undetermined intent (X60 – X84)
20-34	Epilepsy (G41 – G41)	Suicide and injury/poisoning undetermined intent (X60 – X84)
35-49	Bacterial pneumonia (J12 – J18)	Malignant neoplasm of breast (C50)
50-64	Down's syndrome (Q90)	Malignant neoplasm of breast (C50)
65-79	Bacterial pneumonia (J12 – J18)	Malignant neoplasm of trachea, bronchus and lung (C33–C34)
80+	Bacterial pneumonia (J12 – J18)	Dementia & Alzheimer's disease (F01-F03, G30)
All females	*Bacterial pneumonia (J12 – J18)*	*Dementia & Alzheimer's disease* (F01-F03, G30)

As Table 11 shows, the leading underlying causes of death for people with learning disabilities are very different from those of the general population. As we commented it our last annual report, by recording Down's syndrome for example as an underlying cause of death, it conceals the more specific causal sequence of events leading to the person's death. This was the case for 655 deaths.

We therefore considered what other causes of death are mentioned on Part I of the MCCD for people whose underlying cause of death was attributed to Down's syndrome (Table 12).

[35] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2018#leading-causes-of-death

Table 12 shows that almost a half (46%) of those with Down's syndrome as the underlying cause of death had dementia or Alzheimer's disease listed elsewhere in Part I of the MCCD; a third (33%) had bacterial pneumonia listed, and a quarter (27%) had aspiration pneumonia.

Table 12: Other causes of death recorded on Part I of MCCD for people with Down's syndrome recorded as the underlying cause of death

(Where ICD-10 codes are available)	**No.**	**%**
Dementia and Alzheimer's disease[36]	301	46%
Bacterial pneumonia	216	33%
Aspiration pneumonia	179	27%
Lower respiratory tract infection	51	8%
Epilepsy	32	5%
Total with Down's syndrome	655	

Leading causes of death conditions mentioned in Part I of the MCCD

Although the underlying cause of death is most commonly used in national statistics, given its perceived inaccuracies in reporting deaths of people with learning disabilities, it is instructive, as we have seen, to consider those conditions that are mentioned anywhere in Part I of the MCCD.

The ten conditions most frequently cited in Part I of the MCCD for 5,996 people with learning disabilities aged 4 years and over for whom we have a verified ICD-10 code for the causes of death are shown in Table 13.

It would seem that addressing these should be the main targets for health promotion policies and strategies for people with learning disabilities.

Table 13: The ten conditions most frequently cited in Part I of the MCCD

	No.	**%**
Bacterial pneumonias (J12 – J18)	1,444	24%
Aspiration pneumonia (J690)	948	16%
Down's syndrome (Q90)	658	11%
Dementia and Alzheimer's disease (F01 – F03, G30)	545	9%
Sepsis (A40 – A41, R65.2)	432	7%
Epilepsy (G40 – G41)	348	6%
Ischaemic heart disease (I20 – I25)	325	5%
Cerebral palsy (G80)	294	5%
Acute lower respiratory infections (J20 – J22)	265	4%
Heart failure (I50)	196	3%

As Table 13 shows, the most frequently reported condition, by some way, was bacterial pneumonia, followed by aspiration pneumonia.

Each of the next four causes of death were separated by approximately 100 deaths: Down's syndrome, dementia and Alzheimer's disease, sepsis and epilepsy. Ischaemic heart disease was reported slightly less frequently than epilepsy.

Down's syndrome was mentioned in Part I of the MCCD for 659 deaths, although, as already mentioned, this is a syndrome and not a disease in itself.

Appendix 5 presents the leading causes of death by region and Clinical

[36] We have merged dementia (a syndrome) and Alzheimer's disease together, as is commonly the case in national data.

Commissioning Group (CCG) where the CCG had ten or more deaths recorded for the specific cause in 2018 and 2019. Any CCGs with fewer than ten deaths for all of the listed leading causes of death have been removed.

Deaths from avoidable (medical) causes

In 2005, the UK Office for National Statistics (ONS) proposed identifying national indicators of avoidable deaths for England and Wales. Following public consultation, a definition of avoidable mortality and a list of causes of death considered to be avoidable were published in 2012; the list of causes of death considered to be avoidable was later revised in 2016; and in 2019 a harmonised definition was created for use across Europe.

In February 2020, the Office for National Statistics published national data for England and Wales using the new definition.

The harmonised definition of avoidable mortality is shown in Table 14.

Note that the definitions relate to underlying medical causes of death, not the circumstances leading to death. Thus, these are 'avoidable causes of deaths' not 'avoidable deaths' per se. To remind the reader about this we have used the term 'medical causes of death' in this section.

Table 14: The new harmonised definition of avoidable mortality	
Preventable mortality	Causes of death that can be mainly avoided through effective public health and primary prevention interventions (i.e. before the onset of diseases/injuries, to reduce incidence).
Treatable mortality	Causes of death that can be mainly avoided through timely and effective health care interventions, including secondary prevention and treatment (i.e. after the onset of diseases, to reduce case-fatality).
Avoidable mortality	Avoidable causes of deaths are all those defined as preventable or treatable.

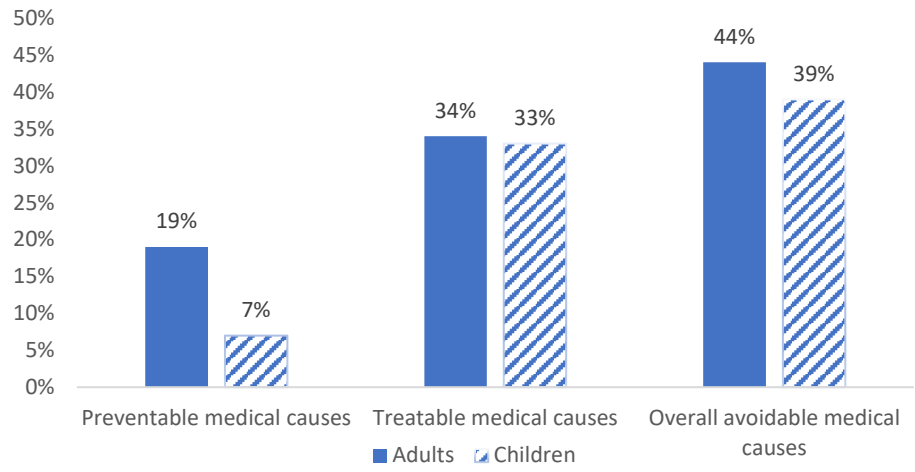
Some conditions, e.g. ischaemic heart disease, are considered to be both preventable and treatable, so proportions may not total 100%.

Figure 11 shows the proportion of preventable, treatable and avoidable medical causes of death for deaths notified to the LeDeR programme before 31st December 2019 for which we have the ICD-10 codes for the cause of death.

Overall, 44% of deaths of adults and 39% of deaths of children were from avoidable medical causes of death.

A third of deaths (34% of adults and 33% of children) are from treatable medical causes of death.

Figure 11: Preventable, treatable and overall avoidable medical causes of death of people with learning disabilities



Preventable medical causes of death

Of the 5,996 deaths, 19% of the underlying causes of deaths of adults and 7% of the deaths of children were from causes of death that could mainly have been prevented through effective public health and primary prevention interventions (Figure 11).

Regionally, preventable medical causes of deaths varied between 16% in the South East to 21% in the North West (Table 15).

Preventable causes of death were more frequently recorded in males (21%) than females (15%) and in white British people (19%) than people from BAME groups (14%). Almost a quarter (23%) of people aged 50-64 at the time of their death had a preventable cause of death, as did almost a quarter of people with mild learning disabilities (24%).

The most frequently recorded preventable causes of deaths were ischaemic heart disease (n=232), aspiration pneumonia (n=132), and stroke (n=74).

Treatable medical causes of death

A third, 34% of the underlying causes of deaths of adults and 33% of the deaths of children were from causes of death that could mainly have been treated with timely and effective health care interventions (Figure 11).

Regionally, treatable medical causes of death varied between 29% in the South West to 35% in the North West, the Midlands and London (Table 15). Treatable causes of death were more frequently recorded in females (35%) than males (32%) and in people from BAME groups (39%) than white British people (33%). Two fifths (42%) of people aged 25-49 years at the time of their death had a treatable cause of death, whereas this was the case for 27% of those aged 65 and over.

There was little difference by the level of a person's learning disabilities.

The most frequently recorded treatable causes of deaths were bacterial

pneumonia (n=495), epilepsy (n=247), and ischaemic heart disease (n=232).

Overall avoidable medical causes of death

Overall, 44% of the underlying causes of deaths of adults and 39% of the deaths of children were from avoidable causes of death that could have been prevented or treated (Figure 11).

Table 15 shows the proportion of avoidable medical causes of death by region. The proportion of avoidable causes of deaths in adults ranged from 38% in the South West to 46% in the North West.

Avoidable causes of death varied by age group. Half (52%) of people aged 25-49 years at the time of their death had an avoidable cause of death, whereas this was the case for 36% of those aged 65 and over.

There was little difference in overall avoidable causes of death by gender, ethnicity or level of learning disabilities.

Table 15: Preventable, treatable and overall avoidable medical causes of death, by region

(Where ICD-10 codes are available)	**Preventable**		**Treatable**		**Overall avoidable**	
	No.	**%**	**No.**	**%**	**No.**	**%**
North West (n=859)	181	21%	300	35%	396	46%
North East & Yorkshire (n=1,098)	219	20%	354	32%	470	43%
Midlands (n=1,069)	192	18%	372	35%	484	45%
East of England (n=692)	128	19%	237	34%	304	44%
South East (n=981)	156	16%	335	34%	415	42%
London (n=703)	127	18%	247	35%	313	45%
South West (n=594)	98	17%	171	29%	223	38%
Total (n=5,996)	*1,101*	*18%*	*2,016*	*34%*	*2,605*	*43%*

Comparison of avoidable medical causes of death between people with learning disabilities and the general population[37]

Table 16 presents the proportions of avoidable deaths for 2018, comparing people with learning disabilities with general population data[38].

It shows that people with learning disabilities died from an avoidable medical cause of death twice as frequently as people in the general population (44% of deaths of people with learning disabilities; 22% of deaths in the general population).

[37]Calculations based on Public Health England's 'Tool for calculating common public health statistics and their confidence intervals' available from: https://fingertips.phe.org.uk/profile/guidance

[38]https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/bulletins/avoidablemortalityinenglandandwales/latest

Table 16: Proportion of avoidable deaths, 2018, people with learning disabilities and general population data[39]						
	Underlying cause of death					
	Preventable		Treatable		Overall avoidable	
	People with learning disabilities	General population	People with learning disabilities	General population	People with learning disabilities	General population
%	19%	14%	34%	8%	44%	22%
Number	502	69,729	921	40,470	1,192	110,198

The greatest difference between people with learning disabilities and the general population was in relation to medical causes of death which are treatable with access to timely and effective healthcare. A third (34%) of deaths of people with learning disabilities were from treatable medical causes, compared to 8% in the general population. – a four-fold difference.

In order to take account of the different age profiles of people with learning disabilities and those in the general population, we have age standardised the data. Age- standardisation allows populations to be compared when the age profiles of the populations are quite different.

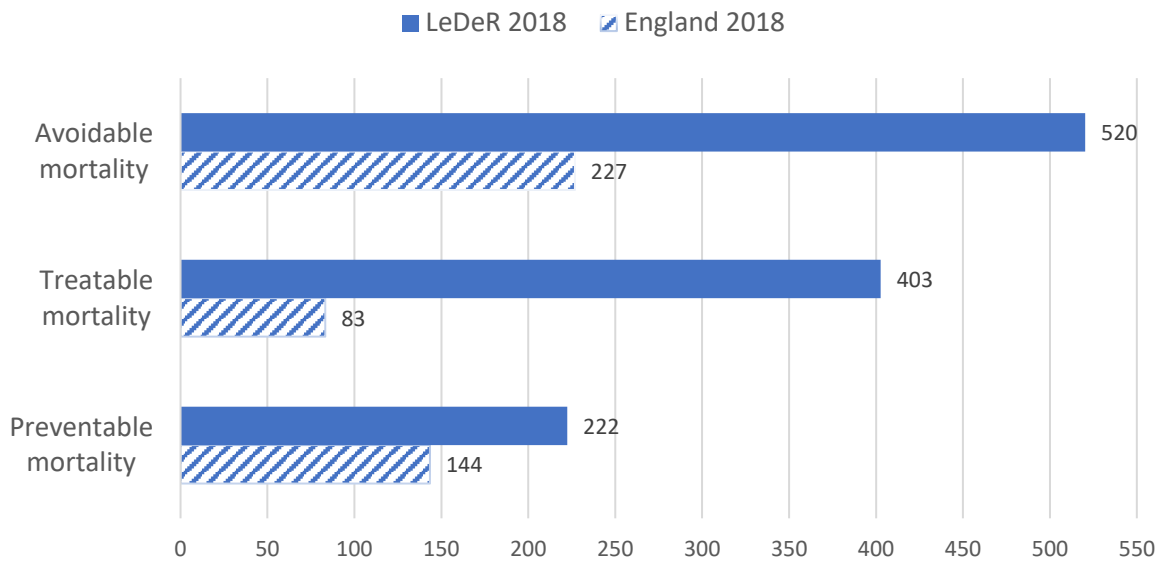
Figure 12 shows the age-standardised rates (per 100,000 population) for avoidable, amenable and preventable medical causes of death, for people with learning disabilities and the general population. It should be noted that the number of people with learning disabilities is comparatively small, so the findings must be regarded as provisional.

Figure 12 indicates that the standardised avoidable mortality rate for people with learning disabilities is 520 per 100,000 compared to 227 for the general population.

The majority of this excess mortality is due to treatable, rather than preventable, causes. Treatable causes account for 403 per 100,000 deaths in people with learning disabilities, compared with 83 per 100,000 in the general population.

[39] NHS Digital data includes people under the age of 4 (excluded from LeDeR) so the lowest age group is slightly under-represented in LeDeR figures.

Figure 12: Age-standardised avoidable, treatable and preventable mortality rates (per 100,000), people with learning disabilities and the general population



Chapter 4

Indicators of the quality of care provided

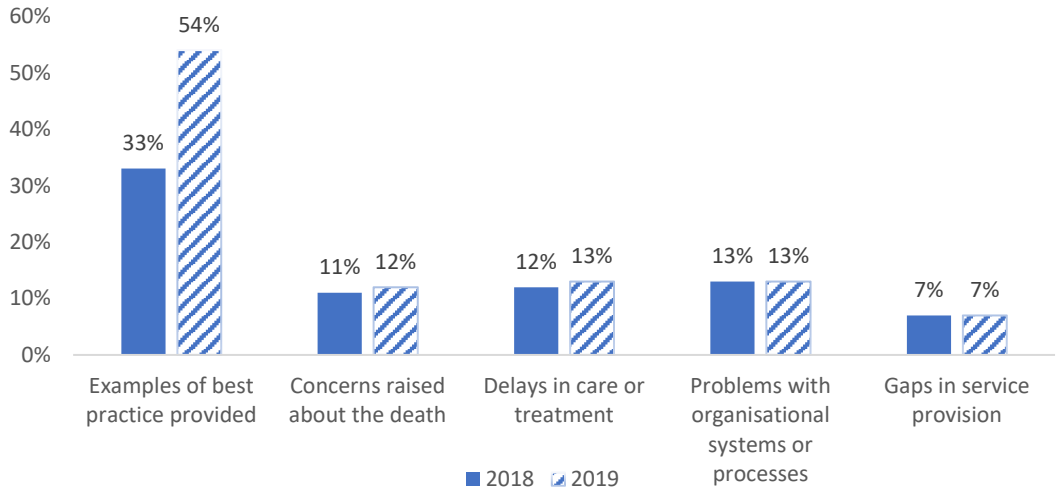
LeDeR reviewers are asked about several different aspects of the quality of care provided, including any best practice, based on what they had learnt. The statutory child death review process does not assess the quality of care in the same way, so children aged 4-17 years have been excluded from the analysis.

Here we consider indicators of the quality of care for the 1,946 deaths of adults reviewed in 2019. These are:

- Examples of best practice provided.
- If there were any concerns about the death.
- If there were any delays in the person's care or treatment that adversely affected their health.
- If there were any problems with organisational systems and processes that led to a poor standard of care.
- If there were any gaps in service provision that may have contributed to the person's death.

Figure 13 shows the indicators of the quality of care reported by LeDeR reviewers, in 2019 compared to 2018. A greater proportion of reviewers provided examples of best practice in 2019 (54%) than in 2018 (33%), but otherwise the proportions for each of the indicators were similar across the time periods.

Figure 13: Indicators of the quality of care received, reviews completed in 2019 and 2018



Examples of best practice

Just over half (54%) of 1,946 reviews of adults completed in 2019 indicated examples of best practice. The proportion was slightly higher for young people aged 18-24 years (58%), but there was little difference by gender, ethnicity or level of learning disabilities.

Many of the descriptions of best practice given by reviewers were of good quality care that anyone should expect to receive.

"Evidence of timely assessment and review by GP as required, consistent annual chronic health condition reviews, annual flu jabs, regular reviews of medication and regular blood testing…. There is evidence that Lucy did have learning disability annual health checks. Timely referral to breast cancer specialist via 2-week wait referral process. Good evidence of use of the Mental Capacity Act in terms of operations, end of life care planning, medical procedures in hospital, change of residency from supported living to nursing care." (reviewer).

Other reviewers gave examples that they felt was beyond good quality care, in which those supporting the individual had 'gone the extra mile' to accommodate their needs. The main areas in which best practice was most frequently mentioned were:

- Person-centred care.
- Multi-agency working.
- Advocacy.
- The use of reasonable adjustments[40].

"The care plan which details how to support Thomas is exceptional. From just this plan, you are able to understand who he was, the care and support he needed, how to understand him, keep him well, comfortable and pain free. It includes photographs and detailed instructions on a number of things including how to position him at different times, to sleep, to relax for example." (reviewer).

"A positive and dynamic multi-disciplinary approach underpinned the care provided to the person and family. Whilst that might be seen as something that should happen automatically, in my opinion, professionals went the extra mile to ensure all support was provided in a timely manner." (reviewer).

"Upon visiting the home, it quickly became apparent that the passion to challenge inequalities in care for people with learning disabilities was an integral culture of the environment." (reviewer).

Problematic aspects of care

Concerns raised about the death

Of 1,946 deaths that were reviewed in 2019, the majority (88%) indicated that no concerns had been raised about the death. Just over one in ten reviews (12%) noted that some concerns had been raised. Concerns were more frequently reported for young people aged 18-24 years (19%) and people from BAME groups (19%).

The concerns originated from a range of sources, including families, social care staff, professionals and the findings of other reviews. There was a wide range of concerns, but they were (as reported in 2018) commonly in relation to:

- Delays in diagnosing and treating illness.
- An apparent lack of care.
- Unsafe discharges from hospital.
- The quality of health or social care received by the person.
- Assumptions being made about the person.

[40] The Equality Act 2010 requires services to make adjustments to the way they support disabled people so that disabled people are not disadvantaged from accessing services.

Each of these themes has previously been identified and reported as being related to potential contributory factors to premature deaths in people with learning disabilities in the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD), LeDeR and other reviews and investigations (see Chapter 6).

"Nelly's sister feels that there was a delay in diagnosing her illness. Nelly's presentation was attributed to behaviour and her condition was initially overlooked. While Nelly's sister acknowledges that her sister would still have died, it would have been in Nelly's best interest to have an end of life care plan and possibly have been moved to palliative care unit sooner than she was." (reviewer).

"The staff at the care provider have raised concerns that when Lydia was admitted to hospital she was asked to sign a DNACPR with no support from either the support workers or her family….Lydia would not have had the capacity to understand the decision to put one in place." (reviewer).

"The family …felt that his care deteriorated once he left children's services and was transferred over to the adult team where he was 'just a number'." (reviewer).

Delays in the person's care or treatment that adversely affected their health

Reviewers were asked if, from the evidence they had, they felt there were any delays in the person's care or treatment that had adversely affected their health.

The majority of reviews (87%) indicated that there had been no such delays, but 13% noted that delays had been apparent. Delays were more frequently reported for people from BAME groups (19%); there was little difference by gender, age group or level of learning disabilities.

The delays described were various, but common themes were:

- Delays in appropriate investigations being carried out.
- Delays in the timely provision of medical care.
- Delays in processes related to the Mental Capacity Act.

Again, each of these themes has previously been identified and reported as being related to potential contributory factors to premature deaths in people with learning disabilities in CIPOLD, LeDeR and other reviews and investigations (see Chapter 6).

"Internal and external investigations of the case have been completed which have identified that earlier surgical intervention and escalation to ITU [Intensive Care Unit] may have changed the outcome." (reviewer).

"He had a cardiology appointment and should then have had a review appointment in 18 months. He was not seen again until four years later." (reviewer).

"There was a seven-month delay in facilitating the initial physical investigations. The cause of the vomiting, weight loss and abdominal

distension was not investigated in a timely manner…The response from professionals to family concerns was too slow." (reviewer).

Problems with organisational systems and processes that led to a poor standard of care

Based on the evidence they had, reviewers were asked if they thought that there were any problems with organisational systems and processes that led to a poor standard of care for the person.

The majority (87%) of reviews reported no such problems, but 13% of reviews did indicate such concerns.

Problems with organisational systems and processes that led to a poor standard of care were more frequently reported for people from BAME groups (22%); there was little difference by gender, age group or level of learning disabilities.

The majority of problems with organisational systems and processes related to:

- Poor coordination of care and information sharing within and across different agencies.

This is also an issue that has been repeatedly raised in relation to the care of people with learning disabilities and its influence as a contributory factor for premature death (see Chapter 6).

"In the 10 days prior to being admitted to hospital where she died, she was visited three times by the community nursing team for pressure ulcer care and venepuncture; three times by paramedics; made three calls to 111; was seen by her GP three times; was admitted to A&E and discharged twice.

[There were] 11 face to face contacts in 10 days. It is not evident Anne had a health care key worker to coordinate and understand these contacts." (reviewer).

"The spiral of interlocking events was taken as individual issues rather than being reviewed in their entirety; the duration, intensity and accumulation of the overall impact was missed." (reviewer).

"The key for this man to possibly still be alive today is because his care was poorly coordinated and assessed, the provider, health and social care professionals all said that people were working in silos…There were different bits of information about this man on different health systems…None of the systems talked to each other or shared their information well." (reviewer).

Gaps in service provision that may have contributed to the person's death

Most reviews (93%) reported no gaps in service provision that may have contributed to the person's death, but 7% did report such gaps.

Gaps were more frequently reported for people from BAME groups (14%); there was little difference by gender, age group or level of learning disabilities.

Such gaps identified a range of issues, including:

- A lack of, or non-referral to, specialist learning disability services.
- A lack of care coordination.
- Out of date social care assessments.

"Referral to the disability and inclusion service could have provided additional support and advice, as well as reasonable adjustments…" (reviewer).

"Lack of hospital-based learning disability liaison nurse or coordinator. There seems to have been no one in the hospital with an oversight of what was happening to him." (reviewer).

"Social care package does not seem to have changed to meet his changing needs." (reviewer).

Overall assessment of the quality of care

At the end of their review, having considered all the evidence available to them, reviewers are requested to provide an overall assessment of the quality of care provided to the person[41].

The grading is as follows:

1. Care met or exceeded good practice.
2. Care fell short of current good practice in one or more minor areas, but this did not significantly impact on the person's well-being.
3. Care fell short of expected good practice in one or more significant areas, but this did not significantly impact on the person's well-being.
4. Care fell short of expected good practice and this significantly impacted on the person's well-being and/or had the potential to contribute to the cause of death.
5. Care fell far short of expected good practice and this contributed to the cause of death.

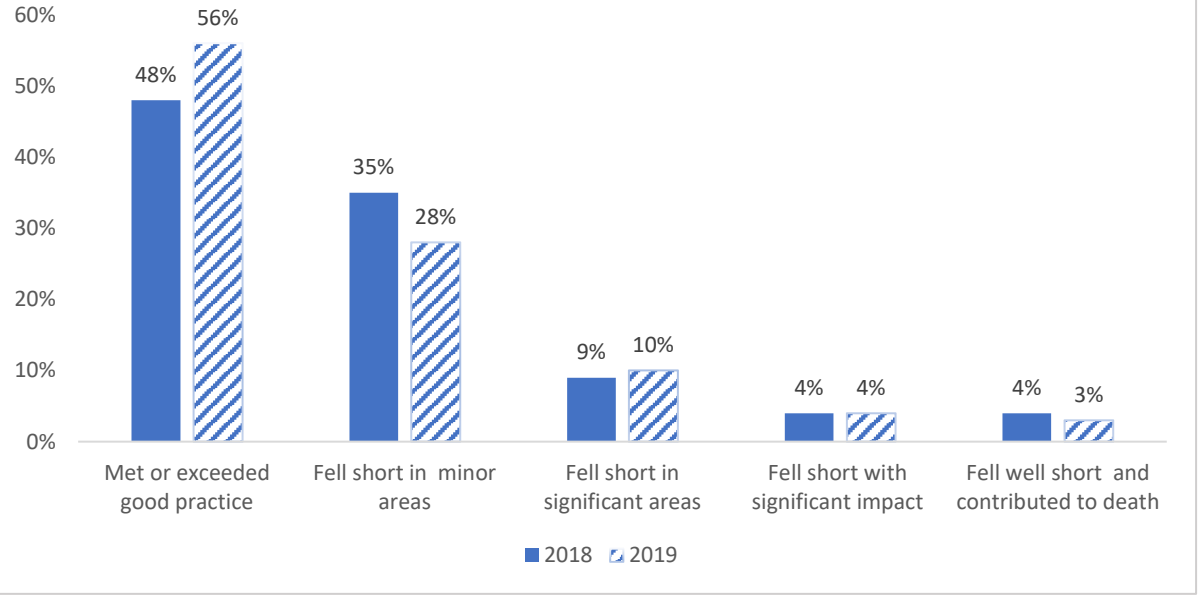
Figure 14 presents the reviewer assessment of the quality of care provided to adults with learning disabilities whose deaths were reviewed in 2019 and 2018.

As Figure 14 shows, a greater proportion of deaths reviewed in 2019 (56%) reported that the person had received care that met or exceeded good practice, compared with deaths reviewed in 2018 (48%).

A similar proportion of people in 2019 as in 2018 were reported to have received such poor-quality care that it significantly impacted on their well-being and/or had the potential to, or actually did, contribute to their cause of death.

[41] The question and grading scale have changed slightly in response to feedback from reviewers and local area contacts over time, so the grading has been reworded slightly to combine different versions.

Figure 14: Reviewer assessment of the quality of care provided to people with learning disabilities, reviews completed in 2019 and 2018 (N.B. Totals may not equal 100% due to rounding)



Care that met or exceeded good practice
Everyone should expect to receive care that meets good practice, but this was the case for just over a half (56%) of reviews of deaths of adults with learning disabilities completed in 2019.

There was little difference in the proportion of people whose deaths met or exceeded good practice according to their gender, age group, ethnic group or level of learning disabilities.

Reviewers described good quality care as:

- Care that had the person's wishes and needs at its centre.
- Care that was proactive and responsive to meeting the changing needs of a person.
- Care that involved good communication and coordination with others, including family members.

"GP was responsive to presenting health issues timely. She was followed up timely and offered appointments quickly. She was referred for diagnostic tests timely and was seen in good time. She was monitored for continence and epilepsy conditions in line with good practice." (reviewer).

"There was a clear integrated package of care in community, adaptive to support her needs and not overtly intrusive allowing her dignity and respecting her wishes." (reviewer).

"Rich received a good level of care and support …with appropriate reasonable adjustments being made for him as his health required. His family were closely involved in his care by all services." (reviewer).

Care that fell short of good practice but without significant impact on the person's well-being
Over a third (38%) of adults with learning disabilities were felt to have received care that fell short of good practice (in minor

or significant ways) but without significant impact on their well-being.

There was little difference in the proportion according to their gender, age group, ethnic group or level of learning disabilities.

The reasons for care falling short of good practice but without significant impact on the person's well-being were often due to:

- Service provision being reactive rather than proactive.
- Poor communication and coordination about a person's care.
- Sub-standard elements of care such as medication management, supporting a person to engage with aspects of their healthcare, application of the Mental Capacity Act, ensuring an appropriate placement for the person, and engagement with families.

"John was in receipt of appropriate services to meet his needs prior to his death. Due to his deteriorating health it would have been advantageous to have some advanced care planning in place and discussions with him and his family members regarding end of life care." (reviewer).

"The care given at the hospital involved multiple specialities, but it was not coordinated in an effective way." (reviewer).

"The review has identified a number of gaps in Leon's care. These include: a lack of …professional curiosity and action in relation to weight assessments and reviews… a lack of understanding of recurrent chest infections cause prevention and management… a lack of documentation in relation to learning disability action plans, mental capacity assessments and Best Interests decisions." (reviewer).

Care that fell so far short of expected good practice that it significantly impacted on the person's well-being or directly contributed to their cause of death

One hundred and twenty-two adults with learning disabilities were reported to have received care that fell so far short of expected good practice that it significantly impacted on their well-being or directly contributed to their cause of death. Each of these deaths would have received further investigation (e.g. safeguarding adults review) and/or a LeDeR multi-agency review.

There was little difference in the proportion according to their gender, age group, ethnic group or level of learning disabilities.

The reasons for falling so far short of expected good practice varied, but predominantly included:

- Problems with care that were related to significant delays in the diagnosis and treatment of illness.
- Omissions in care.

"The Structured Judgement Review states that this death might have been avoided if admitted and treated on [date]." (reviewer).

"Earlier medical intervention was needed for Gordon's constipation and the pain and the discomfort it caused – this impacted on his wellbeing and may have been a potential contributory factor to the cause of death." (reviewer).

"Mr Smith required significant additional support to ensure his health needs were met following reports of chest pain and the potential seriousness of this symptom. Ensuring attendance to a follow up appointment may have contributed to improved outcomes. There was a lack of a coordinated health and social care approach to Mr Smith's health." (reviewer).

Multi-agency review panels

Multi-agency review panels reviewed 117 deaths in 2019. Issues discussed most frequently by the review panels were:

- The understanding that people had about supporting those with learning disabilities.
  Panels discussed general understanding about people with learning disabilities, the potential needs of a person with learning disabilities, and the need for mandatory learning disabilities awareness training for health and social care staff.

- Care coordination and communication between services.
  Panels discussed communication between services; record keeping and information sharing; actions taken when a person did not attend an appointment; referral pathways to the learning disabilities team and other specialist services (e.g. speech and language therapists); and assigning a key worker to coordinate care.
- The application of key legislation.
  Panels discussed staff understanding of the Mental Capacity Act (2005), including assessing and documenting capacity and Best Interests decision-making processes; and staff understanding of the Equality Act (2010), including the provision and documentation of reasonable adjustments.

- Systems and processes.
  Panels discussed the need for 'joined up' NHS and social care information technology systems; and the flagging that a person had learning disabilities across the health and social care sector.

- Safeguarding.
  Safeguarding issues discussed included staff training about sepsis, pneumonia, dysphagia, and recognising end of life needs; the recognition of safeguarding issues; and making safeguarding referrals.

After reviewing on the sequence of events leading to the person's death, panels then reflect, jointly, on a series of questions about any contributory factors to the death that may have been potentially avoidable.

Potentially avoidable contributory factors

Potentially avoidable contributory factors to a death relating to the person's care and its provision were identified in 61% (n=71) of deaths reviewed by a multi-agency meeting. These included issues relating to:

- The provision of appropriate nutrition.
- Failure to recognise or respond appropriately to early signs of deterioration.
- Errors or omissions in the provision of care.

"There was inconsistency in clear recording of the consistency of food to

be offered – either pureed or soft mashable. A large piece of carrot was identified as causing an obstruction to the airway which may have contributed to his cause of death." (reviewer).

"There was a delay in diagnosing the seriousness of her physical illness, both prior to her hospital admission as well as once in hospital. It is possible that this led to the deterioration in her physical health and ultimately multi-organ failure." (reviewer).

"Adam received venous thromboembolism (VTE) routine risk screen for possible deep vein thrombosis (DVT) / pulmonary embolism due to decreased mobility… Medication was prescribed but not administered…It was documented that sepsis and /or dehydration could also have contributed to the development of fatal VTE for Adam." (reviewer).

Potentially avoidable contributory factors to a death are also considered in relation to the way services were organised and accessed. Such factors were identified in 62% (n=73) of deaths reviewed by a multi-agency meeting.

These included issues relating to:

- How different agencies worked together to support an individual.
- Training needs of staff.
- Clarification for staff about how to follow the Mental Capacity Act in practice.

"There were difficulties relating to sharing of information across Haleema's support network…eg at times the rapid response team went to see Haleema, but they use a different computer system, so the GP surgery were not always aware when they had visited or what action had been taken." (reviewer).

"While there were many services involved in Bruce's care, it seems the care home and GP became isolated ...the home did not consider contacting the funder of the placement and services did not coordinate their views and practice… the panel felt this might have led to earlier neurological oversight in this case…" (reviewer).

"Had staff been appropriately trained around sepsis and deteriorating patients, they could have phoned earlier for emergency services and there is a possibility that earlier intervention could have prevented Andrew's death." (reviewer).

Potentially avoidable deaths

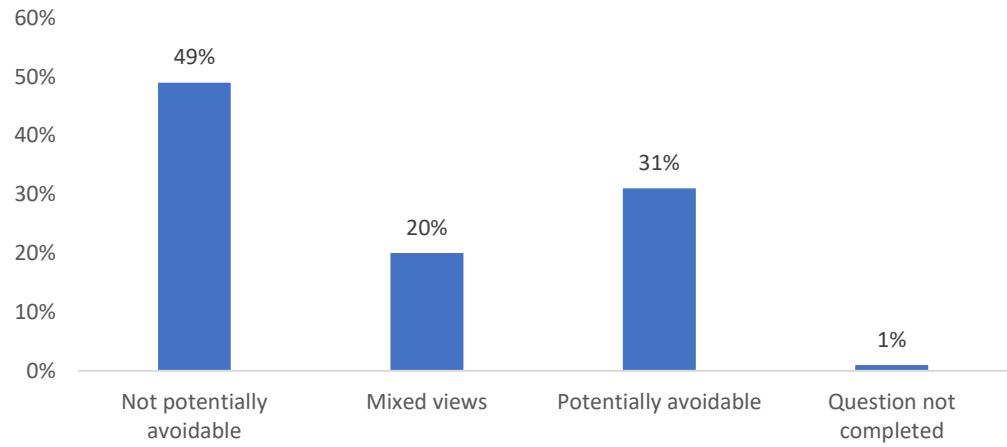
Potentially avoidable deaths are those where there are aspects of care and support that, had they been identified and addressed, may have avoided the person dying at that time from that cause.

Figure 15 shows the proportion of multi-agency review panel decisions about whether the death was potentially avoidable, for reviews completed in 2019[42].

[42] We have not included data from 2018, as they are not directly comparable. In 2018, multi-agency review panel meetings were routinely held for deaths of young people aged 18-24 years, and people from BAME groups. This stopped in 2019.

Of the 117 deaths reviewed in multi-agency review panels, half (49%, n=57) reported that the death was not potentially avoidable. Almost a third (31%, n=36) felt the death had been potentially avoidable. The panel could not reach a unanimous decision on a further 20% (23 deaths). The question was unanswered by fewer than five panels.

Figure 15: Multi-agency review panel decisions about whether the death was potentially avoidable, reviews completed in 2019



Lessons learned were identified in 92% (n=107) of deaths reviewed by multi-agency panels.

Examples of some of the recommendations made by multi-agency review panels are given in Appendix 6.

Chapter 5

Focus on specific issues

Family involvement in decision making via formal Best Interests processes

The Mental Capacity Act 2015 (MCA)[43] clarified the law in England and Wales about how decisions should be made on behalf of those who lack mental capacity. It was accompanied by a Code of Practice providing guidance on the implementation of the five key principles of the Act.

Essentially, the Act requires that if it is established that a person lacks the capacity to make a specific decision, the decision must be made in their 'Best Interests'.

The 'Best Interests' decision-making process requires consultation with close relatives or friends and anyone engaged in caring for them, as well as anyone previously named by the individual, an attorney appointed under a Lasting Power of Attorney or Enduring Power of Attorney, or a deputy appointed by the Court of Protection to make decisions for the person.

The consultation should seek to establish the views of the person themselves in relation to the specific decision that needs to be made – considering their previously stated and current wishes and feelings, any beliefs or values they hold, and the things that they would take into account if they were making the decision for themselves.

In addition, everything possible should be done to encourage the person to take part in the decision-making, including if necessary, postponing the decision until they are able to contribute to it. The Act specifies that assumptions should not be made on the basis of age, appearance, condition, or behaviour.

It is clear from the Act that close relatives and those caring for the person should be expected to 'put themselves in the shoes' of a person without the capacity to make a specific decision, and to contribute their views about what they think the person would want.

In this section we present evidence[44] from LeDeR reviews about the involvement of families in decision-making via apparent formal Best Interest decision making approaches as required by the MCA.

Evidence of good practice

Many of the reviews appeared to indicate good practice. In situations where a person had been assessed as lacking capacity, good practice would involve:

- Consultations with their family who may be able to explain what the person would want.
- Reassessing the person's capacity at appropriate points and in relation to different decisions.
- Involving the person themselves as much as possible.
- Keeping people informed of what is happening in relation to the decision.

Examples that were noted as good practice by reviewers also included where

[43] http://www.legislation.gov.uk/ukpga/2005/9/introduction

[44] The illustrative examples are drawn from the 'pen portraits' of the individuals who have died and the reviewer accounts of the circumstances leading to the person's death using the words that reviewers have used (as much as possible) to avoid any potential bias in our reporting.

relatives and professionals were in frequent contact with health and care staff, where it was re-confirmed that the family members were still of the same opinion, and where consultations involved of a network of people who knew the person.

> "Evidence that there was understanding of the change in her care needs and involving her family, MDT [multi-disciplinary team] and IMCA[45] [Independent Mental Capacity Advocate] with all decision making at all times. Best Interest meetings were carried out when it was deemed that she lacked capacity in understanding her treatment and her family were always involved… Involvement of an IMCA when she needed her placement to be changed…When she lacked capacity, Best Interests decisions were made on her behalf with the involvement of her family." (reviewer).

Indications that families were thinking about what the person would want included reference to considerations about whether a person was able to 'cope' with a potential treatment or experience, how they would 'respond' to particular circumstances, what their 'wishes' would have been should they be in a position to make a choice about the matter, and how their 'quality of life' would be affected in relation to what they believed/felt/enjoyed etc.

> "The decision to not use [tube] feeding was recorded as a Best Interest decision. This appeared to be discussed with the right input from professionals …who had known Jane for some time. It also involved her brother. There was evidence that it was a balanced discussion where they really were trying to do the best thing for her. They thought about how she might respond to a …tube…" (reviewer).

Decisions made without following Best Interests decision-making processes

The majority of reviews studied referred to some family involvement in decision making. However, there were also examples of instances where Best Interests processes were not followed, either because the wishes of family members alone were followed by professionals without broader consideration, or families were excluded from the decision-making process.

There were a number of examples where there appeared to be an over-reliance on the views of families, rather than this being part of a Best Interests decision-making process. Miriam's mother, for example, was often consulted when decisions needed to be made and was '*assumed to be the decision maker for Miriam',* refusing respite and care management reviews for Miriam.

> "…there was an acceptance that mum's wishes be followed rather than adherence the Mental Capacity Act." (reviewer).

In contrast to an over reliance on the opinions of family members, some families appeared to be excluded from decision making processes altogether. Examples of this were in relation to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions being

[45] The Mental Capacity Act 2005 introduced the role of the independent mental capacity advocate (IMCA). IMCAs are a legal safeguard for people who lack the capacity to make specific important decisions, such as where they live or serious medical treatment. IMCAs usually represent people where there is no one independent of services, such as a family member or friend, who is able to do so.

completed without consultation, and decisions about surgery failing to include families who were actively involved in the life of the person.

> "…there is a letter from the Cardiologist to the GP that states he didn't discuss the heart murmur as she [Malik's mother] had enough to deal with… Surgeon records that he is unsure whether Malik does understand the risks and benefits of surgery. No formal capacity assessment is undertaken…Mum reports services did not use her as an advocate in Best Interest decisions made." (reviewer).

Apparent challenges in engaging families in decision making under the Mental Capacity Act

It appeared that engaging families in decision-making under the MCA involved challenges for some professionals.

One challenge mentioned by some reviewers was the difficulty of contacting a family member because the family member was themselves too unwell for a discussion, they had not been in contact with the person for a number of years, contact details were out-of-date, or they were overseas and out of contact.

Another issue mentioned in some reviews concerned the appropriateness of some family members in decision-making. One reviewer, for example, felt that a person's mother who was in the early stages of dementia, was being '*coerced*' into agreeing with a decision, and questioned the mother's ability to really represent the wishes of her daughter.

A further issue was when there were disagreements between those involved in contributing to a decision. Where disagreements between family members were mentioned, they seem to have been in relation to '*complex family dynamics'* that professionals had to negotiate. In circumstances such as these, the professionals seemed to have taken the varying views into consideration by following up on the concerns of individuals, bringing the family together for a discussion, or obtaining a second opinion.

Another issue identified by reviewers was of ensuring that families understood the decisions to made. It seems evident from some of the reviews that families were, at times, unclear about some aspects of the decisions that were being made, and there was a need for professionals to spend more time and care ensuring that families had a good understanding of the issues at stake.

> "Ashley's sister was asked to sign this (DNACPR) form. Initially she thought the form meant that fluids and medication was being withheld from her sister and she became distressed by this. She claimed that the forms had not been fully explained to her by the ward doctor. Once this had been fully explained she understood it related to CPR [cardiopulmonary resuscitation] she felt okay signing the form. The doctor apologised for not explaining the form clearly to her." (reviewer).

Not only was it important for the family to understand the decisions to be made, some families did not fully understand the MCA decision-making process and their role within this. For some families, this lack of knowledge was particularly evident as their child moved into adulthood and the MCA became relevant from the age of 16. Prior to the age of 16 families had been the decision-maker for their child; after this age decisions should be made

under the MCA, but some families had not appreciated this.

> "She had just transitioned from children's to adults' services and the parents found this difficult. …The family felt no one had explained to them the process [of decision-making] or mentioned the Mental Capacity Act." (reviewer).

The length of time taken to make a Best Interests decision

A small number of reviewers commented on the length of time it took to make a Best Interests decision that adequately involved relevant contributors, including family members or Independent Mental Capacity Advocates (IMCA). It was difficult sometimes for professionals to arrange a time to gather the views of those who knew a person, or to arrange a meeting of relevant people, although some reviewers interpreted this as being a rather more conscious effort to avoid making the decision.

> "The home manager and [Zane's] father felt the [Best Interests] meeting took too long to arrange, approximately six months, and Zane passed away a couple of weeks before the meeting was due to happen. The Community Nurse who had arranged the meeting said it took so long to book the meeting as the consultants at the hospital kept passing it on to other doctors. She felt they did not want to take responsibility for the decision." (reviewer).

Other delays were experienced when IMCAs were not available or did not attend relevant meetings, or when there was confusion about who the decision-maker was.

> "The Consultant should have been the decision maker …but instead asked social care staff and the GP to make the decision and inform him of their decision. This led to a delay in the decision… Len died five weeks after the Best Interest meeting was first discussed and nine days after it took place." (reviewer).

Following the decisions made in a person's Best Interests

In general, there seemed to be an assumption that once a decision had been made it would be implemented. There was evidence from one review, however, expressing concerns that relatives were '*making decisions on behalf of their family members that lack capacity*' even after a Best Interests decision had been made. In this case, a Best Interests decision had been made about improving the person's posture with the use of a mobility aid, but the relatives did not allow the person to use the mobility aid because they believed it to be unsafe and a risk to others in the family home.

Summary of specific recommendations about the involvement of families in Best Interests decision making

There has been a plethora of recommendations about improving adherence to the MCA from other reports and inquiries. Some of these are included in Chapter 6.

One could argue, that had the previous recommendations been implemented and followed, many of the issues identified in the LeDeR programme may have been avoided.

The families who took part in consultation meetings were clear that work to bring

about the implementation of earlier recommendations needs to be prioritised.

These include:

- MCA advice to be easily available 24 hours a day.
- The Department of Health and Social Care should address as a matter of urgency the issue of low awareness about the MCA among those affected, their families and carers, professionals, and the wider public.
- The standards against which the CQC inspects should explicitly incorporate compliance with the MCA, as a core requirement that must be met by all health and care providers.
- The Government work with professional regulators and the medical Royal Colleges to ensure that the Act is given a higher profile.
- Local services to strengthen their governance in relation to adherence to the MCA and provide training and audit of compliance 'on the ground' so that professionals fully appreciate the requirements of the Act in relation to their own role.

In addition, families and people with learning disabilities proposed the following recommendations:

- The need for consistent and accurate guidance for families and people with learning disabilities, available in a variety of different formats. This should be at two levels:
  1) core, consistent information about the MCA and its general requirements
  2) specific knowledge that is required at the time a decision needs to be made.
- Families, and people with learning disabilities themselves, as well as professionals, require a national, authoritative, independent source of advice if they have queries about the process of decision-making or adherence to the MCA.
- Recommendations about the appropriateness of those consulted about decisions made in a person's Best Interests need to be strengthened. Some self-advocates considered that families may sometimes only have a partial view about the wishes of their relative; may not know how the person responds outside the home; may have low expectations about their capabilities; or may not realise how much the person could achieve if given the chance.

Deaths from pneumonia[46]

Introduction

The most common cause of pneumonia is an infection by bacteria or germs. Some pneumonia is caused by a virus. Less commonly it is caused by a fungal infection[47].

Aspiration pneumonia is a type of pneumonia caused by breathing in food, liquid, saliva, or vomit into the lungs, instead of it being swallowed and going into the stomach. The inhaled solids or liquids leads to lung injury and resultant bacterial infection.

Deaths are usually coded as being due to aspiration pneumonia when there has been witnessed episode(s) of inhaling food or drink. There may, however, be some deaths coded as being due to bacterial pneumonia that were related to aspiration, but which were not coded as such; thus, deaths from aspiration pneumonia are likely to be conservatively estimated and we have considered both types of pneumonia together here.

As we have seen in Chapter 3, pneumonia was the most frequently recorded cause of death in people with learning disabilities whose deaths were reviewed in 2019, as was the case in previous years. Here we take a closer look at deaths notified to the LeDeR programme up to 31st December 2019, for which we all notified deaths for which we have cause of death data, and whose deaths were coded as pneumonia (J12-18) or aspiration pneumonia (J690) anywhere in Part I of the MCCD.

Much of the information available is captured from the pen portrait or timeline of a completed review. Some topics that would be relevant to consider in relation to pneumonia (e.g. if the person had good dental health; if they needed postural support; if they had dysphagia) are questions that are not routinely asked in all reviews of deaths, and as such, reviewers may comment, for example, on dental health if it is a problem, but are unlikely to mention it as a matter of course. Where there may be such potential bias, we have included relevant information as provided in individual examples only.

People who died from pneumonia

ICD-10 codes for the cause of death were available for 5,607 adults and 389 children notified to the LeDeR programme between 1st July 2016 and 31st December 2019. Table 17 shows the proportion of deaths from bacterial pneumonia and aspiration pneumonia.

[46]Pneumonia is inflammation of the air sacs (alveoli) in the lungs, causing the air sacs to fill with fluid or pus, making it difficult to breathe in enough oxygen for the body's needs. Common symptoms of pneumonia include a cough, difficulty breathing and a high temperature.

[47] We have combined all types of bacterial, viral and fungal pneumonia and called it 'bacterial pneumonia' to distinguish it from aspiration pneumonia.

Table 17: Proportion of deaths with bacterial pneumonia or aspiration pneumonia coded anywhere in Part I of the MCCD						
	All deaths notified		Deaths notified in 2018		Deaths notified in 2019	
	Adults %	Children %	Adults %	Children %	Adults %	Children %
Bacterial pneumonia	25%	18%	25%	16%	24%	20%
Aspiration pneumonia	17%	3%	16%	2%	17%	3%
Number	*5,607*	*389*	*2,374*	*167*	*2,007*	*155*

As Table 17 shows, the proportion of those who died from bacterial pneumonia or aspiration pneumonia was lower in children aged 4-17 years; 18% of those aged 4-17 died from bacterial pneumonia, and 3% died from aspiration pneumonia, smaller proportions than the deaths of adults from bacterial pneumonia (25%) or aspiration pneumonia (16%).

The proportions were similar in 2019 and 2018 with little change over time.

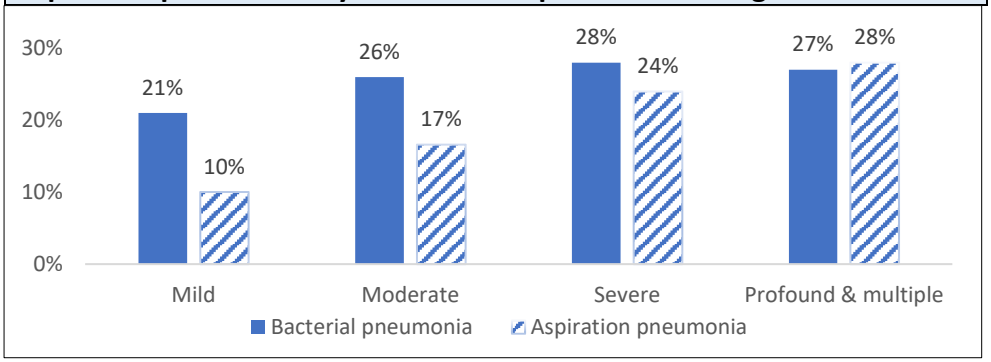
The proportion of deaths from bacterial pneumonia or aspiration pneumonia was also related to the level of a person's learning disabilities (Figure 16).

- The proportion of deaths from bacterial pneumonia was least in people with mild learning disabilities (21%), rising to 28% in people with severe learning disabilities, and 27% in people with profound and multiple learning disabilities.
- The proportion of deaths from aspiration pneumonia was least in people with mild learning disabilities (9%), rising with the level of learning disabilities to 28% in people with profound and multiple learning disabilities.

As Figure 16 shows, over a quarter of people with profound and multiple learning disabilities had bacterial pneumonia coded as a cause of death; a similar proportion had aspiration pneumonia coded.

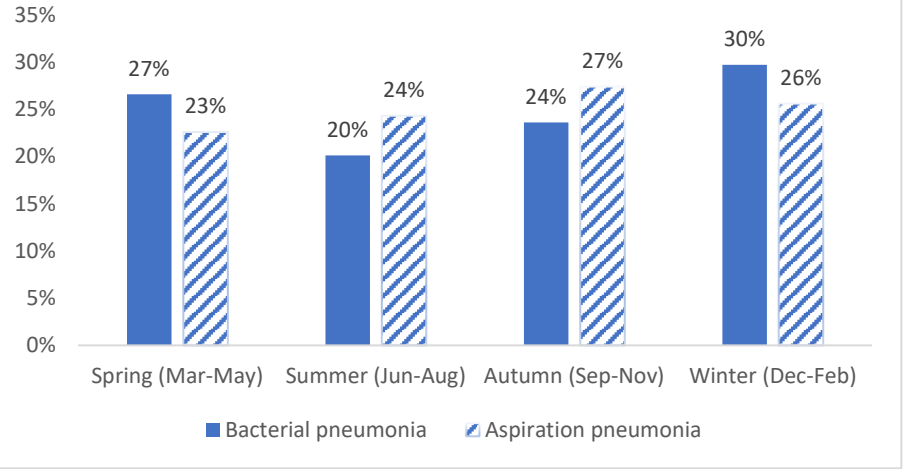
There was little difference in the gender or ethnicity of those who died from bacterial pneumonia or aspiration pneumonia, nor of the geographical region in which they lived.

Figure 16: The proportion of deaths from bacterial pneumonia or aspiration pneumonia by the level of a person's learning disabilities



The greatest proportion of deaths from bacterial pneumonia occurred in the winter (December – February) (30%) and spring (March – May) (27%). The greatest proportion of deaths from aspiration pneumonia occurred in the autumn (September – November) (27%) and winter (December – February) (26%) (Figure 17).

Figure 17: The proportion of deaths from bacterial pneumonia or aspiration pneumonia by the season of the year



The quality of health or care provision of people who died from bacterial pneumonia or aspiration pneumonia

LeDeR reviewers are asked about several different aspects of the quality of care provided, including any best practice, based on what they had learnt.
Here we consider indicators of the quality of care for the 1,163 adults with bacterial pneumonia or aspiration pneumonia mentioned in Part I of the MCCD.

Examples of best practice provided
Examples of good practice were reported in 42% of completed reviews of deaths of people from bacterial pneumonia, and 45% of completed reviews of deaths of people with aspiration pneumonia. The examples of best practice specifically related to:

- Risk or treatment of either form of pneumonia that included proactive and early involvement of a Speech and Language Therapist.
- The provision of timely and coordinated care.
- Regular reviews of dysphagia risk.
- Early recognition of, and response to, physical and behavioural signs of illness.

"Robert's quality of life was improved while living at care home …staff were aware of his initial symptoms which were often behavioural and not related to body temperature or cough." (reviewer).

"There was a reduction in the need for hospital admissions from chest infections or pneumonia over a period of 12 months…due to prompt action to avoid aspiration when he had episodes of vomiting and chest physiotherapy given twice daily." (reviewer).

Concerns about the death

Concerns about the death were reported in the completed reviews of 11% of people who died from bacterial pneumonia and 10% of those who died from aspiration pneumonia.

Those in relation to either form of pneumonia included:

- The diagnosis of pneumonia itself.
- What the person was being fed (e.g. un-thickened drinks).
- How the person was being fed (e.g. lying down), in contradiction of Speech and Language Therapist guidelines.

> "Speech and Language Therapy services were concerned that the GP was not asked to visit Alex at home, as they had advised, and that this had adversely affected his health. The GP had spoken to the home but determined it was not urgent and did not make a home visit. Had he attended it seems likely that antibiotics would have been prescribed sooner." (reviewer).

Delays in the person's care or treatment that adversely affected their health

Delays in the provision of care or treatment that adversely affected a person's health and care were reported in the completed reviews of 12% of people who died from bacterial pneumonia and 13% of people who died from aspiration pneumonia. Delays included:

- Determining the person's nutritional status and securing reliable feeding arrangements for them when they were at risk of aspirating.
- Conducting investigations such as chest X rays.

> "The care home had not arranged chest X rays despite two requests from the GP." (reviewer).

Problems with organisational systems and processes that led to a poor standard of care

Problems with organisational systems and processes that led to a poor standard of care were reported in the completed reviews of 13% of people who died from bacterial pneumonia and 14% of people who died from aspiration pneumonia.

Such problems included:

- Confusion about decision-making processes, including the application of the Mental Capacity Act for people at risk of aspiration.
- Referrals for the insertion of Percutaneous Endoscopic Gastrostomy (PEG) not taking into account the urgency of a situation.
- Poor communication between agencies about a person's care plan.
- Poor processes for proactive planning for a person's health and care needs following previous episodes of pneumonia.

> "There was some delay in gastro team referral for PEG consideration, and the gastro team realising that this was urgent. This led to Henry being without nutrition for up to 9 days, possibly longer." (reviewer).

Gaps in service provision that may have contributed to the person's death

Gaps in service provision that may have contributed to the person's death were reported in the completed reviews of 5% of people who died from bacterial pneumonia and 6% of people who died from aspiration pneumonia. These included gaps in:

- Training and knowledge about dysphagia.
- The need for more clarity about care plans, particularly in relation to feeding.

"There was a lack of physiotherapy to assist with postural care in relation to swallowing and exercises." (reviewer).

Overall grading of the quality of care

At the end of their review, having considered all the evidence available to them, reviewers are requested to provide an overall assessment of the quality of care provided to the person.

For those deaths related to bacterial pneumonia, reviewers felt that just over half (54%) met or exceeded good practice. For 45 (7%) of the deaths, the reviewers considered that the person's care had fallen short of current good practice with the potential for, or actual harm to the person that may have contributed to their death.

For the deaths related to aspiration pneumonia, reviewers felt that half (51%) met or exceeded good practice. For 32 (7%) of the deaths, the reviewers considered that the person's care had fallen short of current good practice with the potential for, or actual harm to the person that may have contributed to their death.

Summary of recommendations specific to bacterial pneumonia or aspiration pneumonia as a cause of death

Many of the action points and recommendations made in relation to deaths from pneumonia were general to their overall care and have been mentioned elsewhere in this report.

Several recommendations were specific to pneumonia. The majority related to improving the training of families, paid carers and professionals about risk factors for aspiration pneumonia. The new Oliver McGowan mandatory training should include this.

Other recommendations were for a national clinical care pathway for people with learning disabilities who have been identified as having a problem with swallowing. This should create clear expectations about the identification, diagnosis and management of people at risk of aspiration pneumonia and provide greater coherence and consistency for the involvement of Speech and Language Therapists and the overall provision of care.

Several recommendations were related to the provision of postural support, particularly when feeding a person in bed or if they were at risk of vomiting.

Others were about the importance of people receiving the pneumococcal vaccine as well as the annual influenza vaccine; of good mouth and dental care (to minimise the risk of inhaling bacteria); and the need to review the effects of anti-psychotic medications on people who are prone to chest infections or at risk of aspiration pneumonia.

"A multi-disciplinary approach to managing the risks associated with aspiration pneumonia is needed. A pathway for the management of people with a learning disability who have repeated admissions for aspiration pneumonia should be developed..." (reviewer).

"The care and management of patients at risk of aspiration pneumonia should be incorporated into annual mandatory training programmes." (reviewer).

"Risk feeding protocols should make explicit reference to seating position while being risk fed." (reviewer).

Deaths from sepsis[48]

As we have seen in Chapter 3, sepsis was the 5th most frequently recorded cause of death in people with learning disabilities in 2019. Here we take a closer look at deaths notified to the LeDeR programme up to 31st December 2019, for which we have cause of death data, and whose deaths were coded as sepsis (A40 – A41, R65.2) anywhere in Part I of the MCCD.

People who died from sepsis

ICD-10 codes for the cause of death were available for 5,607 adults and 389 children notified to the LeDeR programme. Table 18 shows the proportion of deaths from sepsis for all deaths notified, and those notified in 2018 and 2019.

Table 18: Proportion of deaths with sepsis coded anywhere in Part I of the MCCD

	All deaths notified		Deaths notified in 2018		Deaths notified in 2019	
	Adults %	Children %	Adults %	Children %	Adults %	Children %
Sepsis	7	9	7	10	7	7
Number	*397*	*35*	*168*	*16*	*149*	*11*

As Table 18 shows, 9% of those aged 4-17 died from sepsis, a slightly greater proportion than the deaths of adults (7%).

The proportions were similar in 2019 and 2018 with little change over time.

The proportion of deaths from sepsis ranged from 6% of deaths in the South East to 10% in the North West.

There was little variation in the proportion of deaths from sepsis by age group (adults only), gender, ethnicity, or level of learning disabilities.

The quality of health or care provision of people who died from sepsis

Here we consider indicators of the quality of care for the 185 completed reviews of adults with sepsis mentioned in Part I of the MCCD.

Examples of best practice provided

Examples of best practice were given in 48% of completed reviews. Some of the best practice described was care that anyone should expect to receive, but included mention of:

- Excellent end-of-life care.
- Good communication between different agencies and with families.
- Appropriate decision-making.
- Responsive care and support.

[48] Sepsis is a life-threatening illness caused by the body's response to an infection. It develops when chemicals in the immune system are released into the bloodstream to fight an infection but go into 'over-drive' and cause inflammation throughout the entire body instead.

"Sepsis pathway commenced in A&E. Frequent discussions with family about treatment and condition. Involvement of family in decision making. Involvement of multi-disciplinary team…Good coordination of clinical care. Good quality documentation. All possible options of treatment were explored." (reviewer).

Concerns about the death

Concerns about the death were reported in 15% of completed reviews. The most frequent themes specific to sepsis were:

- The timeliness of the diagnosis and treatment of sepsis.
- The inadequate support that was being provided to the person prior to becoming ill.

"Phillip's sisters have expressed concerns that when their brother was admitted to A&E the consultant had advised them that Phillip would be prescribed oral antibiotics and he would be discharged home…when Phil was not discharged home…he was not given antibiotics as recommended by the A&E doctor. They wonder if their brother had been given the antibiotics as suggested by the A&E doctor his outcome would have been different. The reviewer did not find any documentation that Phillip was placed onto a sepsis pathway..." (reviewer).

Delays in the person's care or treatment that adversely affected their health

Delays in the person's care or treatment that adversely affected their health were reported in 16% of completed reviews. Those that were specifically related to sepsis included:

- Delays in diagnosing and treating the person.
- Delays in escalating concerns about the person.

"There was a delay in considering sepsis and treatment was only started after 20 hours in A&E." (reviewer).

Problems with organisational systems and processes that led to a poor standard of care

Problems with organisational systems and processes that led to a poor standard of care were reported in 16% of completed reviews. Those specific to deaths of people from sepsis predominantly related to:

- Problems prior to the development of sepsis, including an absence of care coordination, problems with the transfer of information, and a lack of adherence to the Mental Capacity Act.
- Problems specific to identifying and treating sepsis that were largely in relation to not following sepsis bundle guidelines.

"Fluids and antibiotics given four hours after admission…but promptly once sepsis evident…Action lies without proscribed timescale in sepsis 6 bundle… No senior medical review in Emergency Department…treatment for sepsis could have been initiated sooner..." (reviewer).

Gaps in service provision that may have contributed to the person's death

Gaps in service provision that may have contributed to the person's death were reported in 8% of completed reviews. Most related to:

- The person's care in general (e.g. reducing risks of infection).
- The availability or use of services.
- The need for greater input from specialised services.

"GP declined to see and treat Ken and told them to go to A&E each time…as he had a specialized condition [but] sometimes mum just wanted someone to listen to his chest." (reviewer).

Overall grading of the quality of care

For the deaths related to sepsis, reviewers felt that fewer than half (47%) met or exceeded good practice. For 14 (8%) of the deaths, the reviewers considered that the person's care had fallen short of current good practice with the potential for, or actual harm to the person that may have contributed to their death.

Summary of recommendations specific to sepsis as a cause of death

Most of the recommendations that were specific to sepsis as a cause of death were in relation to training needs:

- For families and paid carers about infection prevention and recognising early signs of sepsis.
- For health professionals about reasonable adjustments that may be needed for the person.

One recommendation was specifically about the need to adapt the New Early Warning Score (NEWS2) to meet the needs of people with learning disabilities.

"Review of sepsis policy and training to ensure [this death] is included in training by the sepsis collaborative." (reviewer).

"Sepsis training to include advice on prevention of infections." (reviewer).

Deaths from epilepsy[49]

As we have seen in Chapter 3, epilepsy was the 6th most frequently recorded cause of death in people with learning disabilities in 2019. Here we take a closer look at deaths notified to the LeDeR programme up to 31st December 2019, for which we have cause of death data, and whose cause of death was coded as epilepsy or status epilepticus (G40-41) anywhere in Part I of the MCCD.

Some topics that would be relevant to consider in relation to epilepsy (e.g. the involvement and expertise of specialist multidisciplinary teams; the monitoring of effectiveness and tolerability of treatments; the content of risk assessment plans) have not been included, other than in individual examples, because they are not routinely asked about everyone with epilepsy.

People who died from epilepsy

ICD-10 codes for the cause of death were available for 5,607 adults and 389 children notified to the LeDeR programme. Table 19 shows the proportion of deaths from epilepsy for all deaths notified, and those notified in 2018 and 2019.

Table 19: Proportion of deaths from epilepsy (epilepsy coded anywhere in Part I of the MCCD)

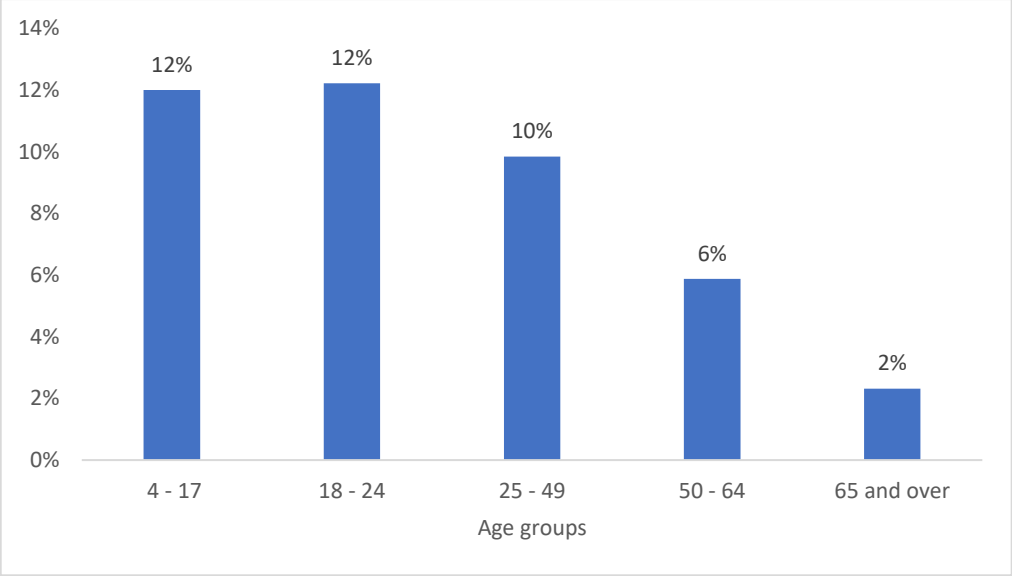
	All deaths notified		Deaths notified in 2018		Deaths notified in 2019	
	Adults %	Children %	Adults %	Children %	Adults %	Children %
Epilepsy	6	12	5	9	6	16
Number	*5,607*	*389*	*2,374*	*167*	*2,007*	*155*

Of all deaths notified to the LeDeR programme for which ICD-10 codes for the cause of death were available, the proportion of those who died from epilepsy was greatest in children aged 4-17 years. As Table 19 shows, 12% of those aged 4-17 died from epilepsy, a greater proportion than the deaths of adults (6%). A greater proportion of deaths of children were from epilepsy in 2019 than in 2018.

The proportion of people dying from epilepsy reduced as age increased: from 12% of children and those aged 18-24 years to 2% of those aged 65 and over (Figure 18).

[49] Epilepsy is a condition that affects the brain and causes frequent seizures. Seizures are bursts of electrical activity in the brain that temporarily affect how it works. Seizures affect different people in different ways but can include uncontrollable jerking and shaking (sometimes called a 'fit'), losing awareness and staring blankly into space (sometimes called an 'absence'), or having strange sensations in the body.

Figure 18: The proportion of deaths in each age group from epilepsy



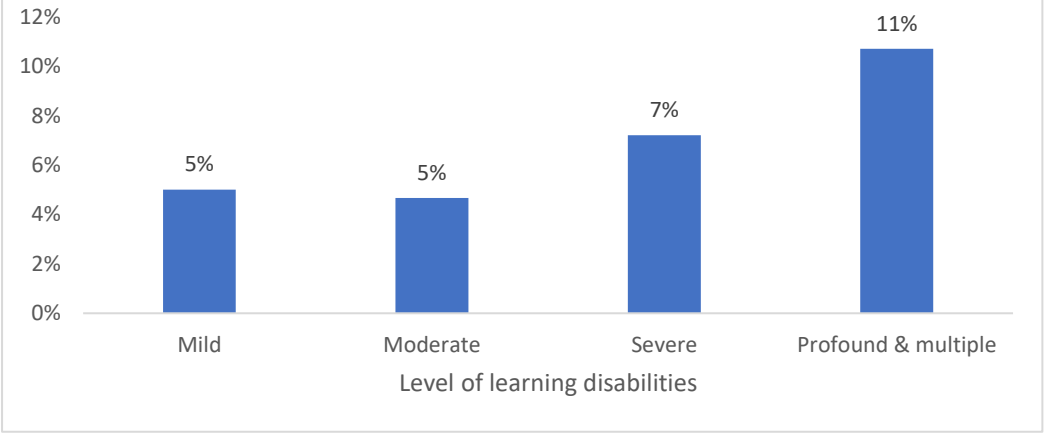
The proportion of deaths from epilepsy was also related to ethnicity and the level of a person's learning disabilities.

A greater proportion of deaths of people from BAME groups were from epilepsy (9%) than were deaths of white British people (6%), but this is largely because adults with learning disabilities appear to be under-represented in notifications of deaths from BAME groups

The proportion of deaths from epilepsy was least in people with mild or moderate learning disabilities (5%), rising to 11% in people with profound and multiple learning disabilities (Figure 19).

There was little difference in the gender of those who died from epilepsy, nor of the geographical region in which they lived.

Figure 19: The proportion of deaths from epilepsy by the level of a person's learning disabilities



The quality of health or care provision of people who died from epilepsy

Here we consider indicators of the quality of care for the 149 completed reviews of adults with epilepsy mentioned in Part I of the MCCD.

Examples of best practice provided

Examples of best practice were given in 43% of completed reviews. The majority of examples of good practice specifically related to epilepsy were noting that the person had received regular reviews of their epilepsy.

> "Rene had very complex epilepsy. Her epilepsy was reviewed consistently by neurology and the epilepsy clinic and records suggest very good communication between neurology the epilepsy clinic and Rene's GP. Rene had an epilepsy care plan which was reviewed consistently and written in plain English. The epilepsy nurse provided training to carers supporting Rene in basic epilepsy awareness and the use of the Vagal Nerve Stimulator. The existence of an epilepsy advice line service provided consistent support to Rene's family in terms of seizure management." (reviewer).

Concerns about the death

Concerns about the death were reported in 11% of completed reviews. The most frequent themes specific to epilepsy were:

- Concerns about the description of death from epilepsy.
- Whether seizure monitoring equipment could have prevented the death.
- That appropriate seizure reporting mechanisms were not in place.
- Concerns raised by families or care staff that changes in seizure patterns had not been acted upon.

> "Brian expressed concerns about the discrepancy between his mother's report of epilepsy being stable and the care home staff reporting increased fits." (reviewer).

Delays in the person's care or treatment that adversely affected their health

Delays in the person's care or treatment that adversely affected their health were reported in 9% of completed reviews. Those that were specifically related to epilepsy included:

- Delays in escalating concerns about changes in seizure patterns.
- Delays in referrals to neurology.
- Delays in administering appropriate treatments.

> "Danny had had several seizures in the week he died, and no medical assistance was sought by staff. There was no clear policy or guidance by the provider to guide the staff on how to manage this. [Seizures were documented eight times]. There was no evidence of actions taken by support staff. There are no indications that the GP was called or that Danny was taken to A&E for medical examination." (reviewer).

Problems with organisational systems and processes that led to a poor standard of care

Problems with organisational systems and processes that led to a poor standard of care were reported in 8% of completed reviews. Those specific to the identification or treatment of people with epilepsy included:

- Poor adherence to the Mental Capacity Act.
- A lack of training for staff about epilepsy.
- Deficient policies about the management of epilepsy.

"The care plan stated that Sandra was to self-medicate and staff to make sure this was happening on a daily basis…No capacity test was undertaken regarding Sandra's understanding of risks of non-compliance with medication…the post-mortem found no traces of medication in her blood." (reviewer).

Gaps in service provision that may have contributed to the person's death

Gaps in service provision that may have contributed to the person's death were reported in 9% of completed reviews. Those specific to risk or treatment of epilepsy included:

- Problems with the provision or repair of seizure alert equipment.
- The provision of training to administer Midazolam.

"Ian had a seizure mat, but it was broken. It had originally been funded by (agency) but there was no contract with them to fix or replace it. Had this been working it may have alerted the sleeping carer." (reviewer).

Overall grading of the quality of care

At the end of their review, having considered all the evidence available to them, reviewers are requested to provide an overall assessment of the quality of care provided to the person.

For those deaths related to epilepsy reviewers felt that 59% met or exceeded good practice. For 11 (7%) of the deaths, the reviewers considered that the person's care had fallen short of current good practice with the potential for, or actual harm to the person that may have contributed to their death.

Summary of recommendations specific to epilepsy as a cause of death

Many of the action points and recommendations made in relation to deaths from epilepsy were general to their overall care and have been mentioned elsewhere in this report.

Several recommendations were specific to epilepsy, however. The majority of these related to the need for better training for those supporting people with learning disabilities, including families and paid staff. Particular aspects of training mentioned included:

- The overall care of a person with epilepsy.
- The importance of good medication management and regular medication reviews.
- Recognition that periods of illness, including fever and diarrhoea, can be risk factors for changes in seizures.
- How to appropriately and adequately record seizures and know when to escalate concerns.
- Protocols for the use of 'rescue' medication when a person has a seizure.

Another theme of the recommendations was the use of seizure alarms which alert someone that the person is having a seizure. Recommendations included ensuring the timely provision of such equipment, ensuring that it was appropriately maintained and repaired, and that staff were able to use it correctly. Other recommendations were in relation to communication and coordination between primary care and neurology services; timely reviews of medication; and local reviews to ensure that services are following NICE guidelines.

"All staff must have epilepsy training which includes the risk of Sudden

Unexpected Death in Epilepsy (SUDEP)." (reviewer).

"There is a need to be sure that sensor equipment is appropriate to the type of seizure the person may experience… where any equipment or technologies are put in place there should be a follow up check to ensure that the agreed equipment has been installed and to check its effectiveness." (reviewer).

"The CCG may wish to consider a review of the Epilepsy Pathway for people with learning disabilities to ensure that care provision is responsive …" (reviewer).

The subset of people for whom Sudden Unexpected Death in Epilepsy (SUPEP)[50] was identified as the cause of death

SUDEP is a difficult cause of death to identify from administrative data. There is no ICD-10 code and therefore no uniform approach to death certification for this condition; most deaths from SUDEP are coded as 'epilepsy' or 'seizure disorder'.

Risk factors for SUDEP include: increased severity and prevalence of seizures in the six months prior to death (especially generalized tonic–clonic seizures); being of a young age (20 - 40); the early onset of epilepsy; an absence of treatment or nonadherence to treatment; changes to antiepileptic drugs; polytherapy; and sleeping[51].

Until the end of December 2019, there were 32 completed reviews where SUDEP was identified as the cause of death. This is a small number of reviews and any findings must therefore be interpreted cautiously.

Of the 149 completed reviews where epilepsy is attributed as the cause of death, deaths from SUDEP account for 21% of the deaths. Most (n=22) of the deaths were determined as being SUDEP by a coroner following a post-mortem.

Males, people from BAME groups, and younger people were over-represented in those who had died from SUDEP. Twenty-three (72%) of the 32 deaths were of males; nine (28%) were from BAME groups; and twelve (38%) were aged 4-24 years old.

The majority (22 of the 32 deaths) occurred when the person was alone in their bedroom, and/or when they were sleeping. Six of these people were noted to have been found 'face down' in their bed or on the floor. The other ten people died in various circumstances, the majority were both in their own home at the time and were alone.

Themes identified in reviews of deaths from SUDEP

There were a number of common themes identified in completed reviews of deaths of people from SUDEP:

- Observed changes in the person prior to death.
- Use of assistive technologies.
- Problems with epilepsy-related care.

[50] SUDEP Action have adopted Nashef et al.'s (2012) definition which draws together the leading definitions: 'Sudden, unexpected, witnessed or unwitnessed, nontraumatic and non-drowning death, occurring in benign circumstances, in an individual with epilepsy, with or without evidence for a seizure and excluding documented status epilepticus (seizure duration ≥30 min or seizures without recovery in between), in which post-mortem examination does not reveal a cause of death'.

[51] Shankar et al. (2018) Decreasing the risk of sudden unexpected death in epilepsy: structured communication of risk factors for premature mortality in people with epilepsy. European Journal of Neurology, 25, 9, 1121-1127.

Observed changes in the person prior to death

The first key theme was of changes being noticed in the person prior to their death. Such changes were most frequently in relation to increased seizure activity, being unwell, and changes to sleeping habits.

A third (34%, n=11) of completed reviews noted that the individual had experienced an increase in their usual seizure activity in the days prior to death.

> "…2 years ago, he started to have more frequent seizures and was referred by his GP back to hospital. In the last few months before his death, Ewan was having 'funny episodes' in the morning feeling dizzy." (reviewer).

Illness-related changes included viruses, ear and neck infections, feeling tired, and changes to sleeping habits. Environmental triggers were also mentioned in several reviews, particularly seizure activity exacerbated by fear of storms and in relation to warmer weather.

Use of assistive technologies

Reference to assistive technologies was a common theme. This included bed mats and devices attached to the bed that provide an alert that the person is experiencing a seizure, wrist alarms and watches worn by a person which can summon help were they to experience a seizure, and monitors that allow others to see or hear the individual at risk of seizures.

The reviewers noted on many occasions that such technologies would have been useful but were, for various reasons, not in use at the time of the persons death. These reasons included:

- The individual or their family refusing to have a seizure sensor fitted in their home.
- The expense of a device.
- The device being present but the individual being away from their home at the time of death.
- Equipment not being maintained and therefore not working at the time of death.
- Assistive technology being planned for but not having been put in place at the time of death.

> "Family have concerns relating to communication of information about use of an epilepsy alarm when their child was moved into her own bedroom. Family had moved their daughter to her own room with the expectation that equipment would be provided. This did not happen." (reviewer).

> "Alex was offered a sensor to be installed in her property that would sound an alarm if she were to have a seizure, but stated that she did not feel that this is necessary…Alex had not purchased an epilepsy watch [as recommended]…as she feels that they are too expensive." (reviewer).

Problems with epilepsy-related care

The final key theme is in relation to a third of reviews (34%, n=11) that noted problems with medications being administered incorrectly or being prescribed at incorrect dosages, refusal to take epilepsy medication, or a failure to provide the person with the expected level of healthcare.

In seven of the 11 reviews, reviewers noted that medication was not taken as recommended. Four of these people were receiving a dose of medication that was

not at therapeutic levels; three were refusing to take their medication at all.

> "The toxicology tests revealed he had 13mg per litre of sodium valproate (his epilepsy drug Epilim) in his blood. The toxicologist noted this is lower than the evidenced therapeutic level of 50 - 100mg per litre." (reviewer).

Most commonly made recommendations

The most commonly made recommendations from SUDEP deaths related to:

- The potential for assistive technologies to have a positive impact in preventing SUDEP.
- A greater need for training about SUDEP in order to risk assess the circumstances in which a person may be most likely to die from SUDEP.

> [There is a] "… lack of clarity around use of recently developed assistive technologies for epilepsy monitoring. Although there are some devices recommended by reputable organisations, there are many more available on the internet, which can be confusing for individuals trying to choose a suitable device"…The recommendation is to "consider what advice and signposting the neurology department offer on assistive technology." (reviewer).

Deaths from specific urgent or ambulatory care sensitive conditions

UCSCs (Urgent care sensitive conditions) and ACSCs (Ambulatory care sensitive conditions) are those that should not regularly require hospital admission if appropriate and timely care is provided. Specifically:

- UCSCs are 'acute exacerbations of urgent conditions which a care system should treat and manage close to home'[52].
- ACSCs are 'conditions where effective community care and case management can help prevent the need for hospital admission'[53].

Whilst emergency admissions for these conditions may at times be necessary, a high rate of admissions is an indication of issues with the accessibility and quality of care provided by primary and community care. Thus, although timely and appropriate care should reduce the need for hospitalisation, we cannot assume that all hospitalisations could be avoided.

Each of the U/ACSCs we consider here is also identified by the new European harmonised definition of avoidable causes of death[54] as being preventable (influenza), treatable (asthma, deep vein thrombosis or pulmonary embolism (DVT/PE)) or both preventable and treatable (diabetes).

Please note, once again, this categorisation refers to medical causes of death; this does not mean that all these deaths are avoidable.

We have included all reviews where one of four conditions (DVT/PE; diabetes; asthma; influenza) were mentioned somewhere in the causal path of medical conditions leading to death, as recorded by the Office for National Statistics on Part I of the MCCD.

We would have liked to include constipation, but constipation is rarely described as a cause of death per se; some deaths from bowel obstruction or volvulus may originate with chronic constipation but are not coded as such. We make a recommendation about this in Chapter 6.

Table 20 shows the number of deaths notified, and reviews completed, for each condition.

Table 20: The number of deaths notified, and reviews completed, for each condition

Condition	Notified deaths as at 31st December 2019	Completed reviews as at 31st December 2019
DVT or PE	145	67
Diabetes	75	32
Asthma	51	28
Influenza	43	25

[52] Nuffield Trust (2019) Potentially preventable emergency hospital admissions. Available from: https://www.nuffieldtrust.org.uk/resource/potentially-preventable-emergency-hospital-admissions#background

[53] NHS England (2014) Emergency Admissions for Ambulatory Care Sensitive Conditions - characteristics and trends at national level. Available from: https://www.england.nhs.uk/wp-content/uploads/2014/03/red-acsc-em-admissions-2.pdf

[54] http://www.oecd.org/health/health-systems/Avoidable-mortality-2019-Joint-OECD-Eurostat-List-preventable-treatable-causes-of-death.pdf

Deaths from deep vein thrombosis / pulmonary embolism (DVT/PE)[55]

There were 145 deaths notified to the LeDeR programme with DVT or PE included in Part I of the MCCD. Of these, 67 reviews had been completed before the end of December 2019.
All but four of those who died from DVT or PE were aged 25 and over; the greatest number of deaths (n=59) was in the age group 50-64 years. A higher proportion of females (3%, n=76) than males (2%, n=69) in the overall deaths notified died from DVT/PE, as did a greater proportion of people with mild (3%, n= 24) or moderate (3%, n=31) than severe (2%, n=14) or profound and multiple learning disabilities (0%, n=0).

There was little difference in the ethnicity of those who died from DVT or PE compared to overall deaths notified to the LeDeR programme.

The greatest proportion of deaths from DVT or PE was in London (3%, n=23 of deaths notified).

The quality of care received by those who died of DVT or PE
Here we consider indicators of the quality of care for the 67 completed reviews of deaths of adults.

Best practice provided
Twenty-six of the 67 completed reviews (39%) described aspects of best practice. These mostly related to aspects of care that anyone should expect, such as person-centred care and timely and appropriate medical attention. Several reviewers noted the provision of advocacy for the individual that they considered to be note-worthy, and evidence of good quality multi-disciplinary working.

> "It is clear from the GP record that he was worried about Martha. The GP raised his concern with the consultant about Martha not receiving certain treatments or investigations and advised his intentions to raise this as a safeguarding concern if it should happen again." (reviewer).

> "The close working between consultants involved both inter-hospital and within the hospital communication was good. This enabled a better understanding of the complexity of Ron's physical conditions..." (reviewer).

Problematic aspects of the person's care
Sixteen of the 67 completed reviews noted concerns about the person's death. These were most frequently from families and care staff about the suddenness of the person's death.

Some concerns related to missed opportunities to prevent the DVT, through better general health and having more exercise; others related to missed diagnoses, or the perceived sub-standard provision of care.

> "Staff stated that they feel that Lincoln's death was a consequence of the poor post-operative advice, support and lack of understanding that he received in hospital, plus the lack of a thorough physical examination at the

[55] Deep vein thrombosis (DVT) is the development of a blood clot in a major deep vein in the leg, thigh, pelvis, or abdomen, which may result in impaired venous blood flow. The symptoms of DVT include throbbing or cramping pain in one leg, swelling in one leg, warm skin around the painful area, red or darkened skin around the painful area, and swollen veins that are hard or sore when you touch them. Pulmonary embolism (PE) is a consequence of thrombus formation within a deep vein of the body, when the blood clot travels to the lungs and causes a blockage. Symptoms include chest or upper back pain, difficulty breathing and coughing up blood.

GP surgery the day before he died." (reviewer).

Sixteen of the completed reviews noted problems with organisational systems and processes that led to a poor standard of care. These most frequently related to poor care coordination, poor quality discharge from hospital, deficiencies in the provision of care, or appropriately reviewing the person when concerns were raised.

"The review team concluded that there were areas of management which fell below acceptable standards, particularly in respect to documentation of capacity assessment and reasons for not pursuing complete observation, monitoring and blood testing…
The omission of one dose of venous thromboembolism prophylaxis is unlikely to have prevented that fatal pulmonary embolism, although theoretically it could have done so. Sepsis and /or dehydration could have contributed to the development of fatal DVT/PE in this patient. A lack of investigations performed on admission meant that these conditions if present were not diagnosed or treated." (reviewer).

Twelve of the completed reviews noted delays in the person's care or treatment that adversely affected their health. Some were related to delays in diagnosing the condition; others were related to delays in accessing specialist services in advance of the condition developing.

Delays in…"involvement by learning disabilities physiotherapist. Christy experienced two falls in June and July. The referral was made in August and the referral picked up in November. Christy was considerably inactive during this time." (reviewer).

Six reviewers commented on gaps in service provision for those who died of DVT/PE. Some of the gaps were in relation to specialist support – from dietetics for support to reduce weight, or from learning disability services to assess capacity for decision-making. Other gaps noted were in relation to communication and listening to the views of those who knew the person best.

"The problem of his obesity was recognised as early as 2007 when his BMI is recorded as 39.6; he had his first consultation with a dietician in 2016 by which time his BMI was already over 52." (reviewer).

Overall grading of the quality of care

Fewer than half (42%, 28 of 67 reviews) considered that the person's care had met or exceeded good practice. Nineteen reviewers thought that the care fell short of current good practice in minor ways. Six people were considered to have received care that fell short of expected good practice with the potential to contribute to the cause of death; six were considered to have received care that fell so far short of good practice that it contributed to their death.

Thematic analysis of completed reviews where DVT/PE was a cause of death

Thematic analysis of the circumstances leading to the 67 completed reviews identified three key issues:

- The risk factor of reduced mobility.
- Signs and symptoms of having a DVT/PE.
- The provision of medical care.

The risk factor of reduced mobility

A large proportion of completed reviews included reference to people experiencing reduced mobility for a variety of reasons prior to their deaths, and it was frequently the case that the people who died from DVT/PE led sedentary lives. There was also a high incidence of obesity that ran alongside the lack of mobility.

Examples from reviews include people sitting for the majority of the day, spending large proportions of their time in bed or in their bedroom, and having physical conditions that limited their ability to move around very much. In some cases, the necessary equipment to improve a person's mobility was not available.

> "Emily had become used to staying in her room as unable to mobilise around anymore… Essential equipment was not installed following Emily's decline in mobility despite several requests…" (reviewer).

Signs and symptoms of having a DVT/PE

It was often the case that there were no clear warning signs that a person had DVT/PE. Some reviews describe the person being themselves, being cheerful and enjoying activities immediately prior to their death. However, there were also examples of people having signs and symptoms of having a DVT or PE prior to their death from this. Some examples of these included people who were coughing, having breathing issues, or having a swollen leg.

> "…Gavin slept for the whole journey and was not singing along with the songs as he usually did when they were travelling on the coach…he also struggled throughout the week with walking from his apartment to the evening meal…." [which was unusual for him]. (reviewer).

Provision of healthcare

There were several issues identified in completed reviews that indicated problems with medical engagement or the provision or receipt of medical treatment. This included, but is not limited to, a lack of adherence to NICE guidelines about preventing venous thromboembolism[56]; a lack of understanding about the support a person needed; and the individual refusing to engage with treatment.

> "It was found that his blood thinning medication was stopped on admission to allow the blood in the urine to settle, however when this resolved, the medication was not restarted. The lack of anticoagulation increased the likelihood of a blood clot forming…[hospital] failed to administer his Edoxaban over a period of days leading to Elijah's death due to pulmonary embolism." (reviewer).

Summary of recommendations specific to DVT/PE as a cause of death

The most commonly made recommendations from reviews of deaths from DVT/PE were in relation to:

- The need for risk factors for DVT/PE to be better recognised and reduced, including the risk factors of immobility and obesity.
- For those at potential high risk of DVT/PE, for additional measures to be in place that help identify if they are experiencing pain, and to familiarise them with medical examination.
- For accessible materials to be available to people with learning disabilities, families and paid carers about the

[56] https://www.nice.org.uk/guidance/CG92

risks of DVT/PE and its early identification.
- For NICE Guidelines about preventing venous thromboembolism to be followed.
- For particular attention to be paid at discharge from hospital, including for post-operative day patients, that families or paid staff are aware of the importance of continuing any anti-embolic medication as prescribed, and can recognise early warning signs of the development of an embolus.

"Venous thromboembolism risk assessment and provision of thromboprophylaxis where appropriate must be completed on admission in all patients." (reviewer).

"Clinicians should be alert to the possibility of differential diagnoses, for example deep vein thrombosis in patients who are clinically obese and present with swollen, erythematous legs, particularly where there are multiple co-morbidities." (reviewer).

Deaths from diabetes[57]

There were 75 deaths notified to the LeDeR programme with diabetes included in Part I of the MCCD. For many of these, 'diabetes unspecified' was noted on the MCCD, making it difficult to distinguish whether a person had Type 1 or Type 2 diabetes.
We have therefore analysed all diabetes together, irrespective of whether they were Type 1 (n=10), Type 2 (n=38) or type 'unspecified' (n=27).

Of the 75 deaths notified to the LeDeR programme, 32 reviews had been completed before the end of December 2019.

Where data are available, all but four of those who died from diabetes were aged 25 and over; the greatest number of deaths (n=58) were in those aged 50 and over. A greater proportion of females (2%, n=40) than males (1%, n=35) in the overall deaths notified died from diabetes, as did more people with mild (2%, n= 20) or moderate (1%, n=15) learning disabilities rather than people with severe or profound and multiple learning disabilities (n=10 or fewer).

There was little difference in the ethnicity of those who died from diabetes compared to overall deaths notified to the LeDeR programme.

The greatest proportion of deaths from diabetes was in the Midlands (2%, n=18 of deaths notified) and the East of England (2%, n= 11).

[57] Type 1 diabetes mellitus is a metabolic disorder in which the pancreas does not produce any insulin. Type 2 diabetes is a progressive disorder in which the body is unable to make enough insulin or the insulin it does make doesn't work properly. Both types of diabetes cause too much glucose (sugar) to collect in the blood which can cause complications. Type 1 is managed by taking insulin to control the blood sugar. Type 2 diabetes is managed by medication, exercise, diet or insulin.

The quality of care received by those who died from diabetes

Here we consider indicators of the quality of care for the 32 completed reviews of deaths of adults.

Best practice provided

Thirteen of the 32 completed reviews (41%) described aspects of best practice. These mostly related to:

- Evidence of good quality multi-disciplinary working.
- The provision of reasonable adjustments.
- Person-centred care.

> "The coordination of her health care, specifically in the last year of her life as this became more complex, was provided by the specialist community learning disability nurse. This provided clear responsibilities across the care community. It was supported with multiple multi-disciplinary health review meetings, involving many consultants and specialists. The coordination provided by the nurse ensured all elements of need had been considered and communicated." (reviewer).

Problematic aspects of the person's care

Seven of the 32 completed reviews noted concerns about the person's death. Some of the concerns related to the cause of death that was reported on the MCCD; others to poor quality discharge from hospital and aspects of care provision.

> There were concerns about the need for "…better …management of diabetes following PEG insertion." (reviewer).

Six of the completed reviews noted problems with organisational systems or processes. Many indicated some confusion about the care plan for the person or an absence of a risk management plan. Others noted problems with the escalation of concerns, and the provision of care.

> "The serious incident report indicates that records and verbal communication between hospital staff contradicted each other on occasions." (reviewer).

Seven reviewers commented on other problematic aspects of the person's care, in relation to delays in the person's care or treatment or gaps in service provision. These were largely in relation to the appropriateness of care provided, the knowledge of care staff about diabetes, and delays in assessments.

> "Letter from hospital to the GP surgery recommended the only way forwards to achieve good blood sugar control would be for William to be on insulin four times per day but as he was reliant on district nurses administering his insulin in his residential home this was not addressed." (reviewer).

Overall grading of the quality of care

Just over half, (53%, 17 of 32 reviewers) considered that the person's care had met or exceeded good practice. Nine reviewers thought that the care fell short of current good practice in minor ways. One person was considered to have received care that fell short of expected good practice with the potential to contribute to the cause of death; two were considered to have received care that fell so far short of good practice that it contributed to their death.

Thematic analysis of completed reviews where diabetes was a cause of death

Thematic analysis of the circumstances leading to the 32 completed reviews identified two key but related issues:

- Assessing mental capacity.
- An emphasis on the choice of a person to make potentially unwise decisions about managing their health.

Assessing mental capacity

There was little evidence that the capacity of people to make apparent choices about their lifestyle had been fully assessed. Where mention was made of the person's capacity to make decisions, it was not always clear that this was in relation to specific decisions.

> "There were long standing and ongoing concerns about Graham's lifestyle and living conditions. He was reluctant to comply with his medication regime and unable or unwilling to maintain his living quarters. Support staff are on record as questioning his ability to manage, but as he had mental capacity, were unable to enforce changes." (reviewer).

Other reviews mentioned that a person's capacity to manage their diabetes had been assessed as lacking, but there appeared to be little appropriate support provided; indeed, in some cases the person appeared to have been treated as though they did have capacity.

> "Nadia found it difficult to manage her diabetes when she lived in her supported living accommodation as different types of food were accessible. She did not have capacity to manage her diabetes without support…. It was difficult for her to manage her blood sugar levels and Nadia eventually required insulin to manage her diabetes…" (reviewer).

A prioritisation of choice

The second key theme was that of a prioritisation of choice. Many reviews focused on the choices that people made about their lifestyles, with no mention of their capacity to make those choices. There were some examples where it was reported that a person's diet was well managed by the individual or those involved in their care and support, but more frequently, a poor diet was reported, referencing in the main the negative consequences of the choices that individuals had made for themselves.

> "Tim chose to eat a poor diet in terms of his diabetes; he wouldn't listen to health advice. He would go to the chip shop for a bag of chips as he loved his food. Tim's parents felt Tim didn't understand his diagnosis and possible consequences of having an unhealthy diet." (reviewer).

Summary of recommendations specific to diabetes as a cause of death

The majority of recommendations where diabetes was a cause of death were about staff understanding and adherence to the Mental Capacity Act, including the need to fully assess capacity for specific decisions, take into account fluctuating capacity and the potential need to reassess capacity if there was a change in circumstances.

> "Staff who work with people with learning disabilities need to ensure a robust understanding of the Mental Capacity Act…there is a difference between an unwise decision and one which an individual does not have the mental capacity to make…failing to carry out a sufficiently detailed capacity

assessment can expose the person to substantial risks." (reviewer).

Additional recommendations were made about the appropriate provision of support for people with diabetes, particularly in community settings.

"The community diabetes team should have a greater involvement with decision-making about care and placement needs for their patients with learning disabilities. Recommendations made by professionals for better control of this patient's diabetes were not acted upon because of the environment he lived in and the support he received. Professionals need to make their recommendations for care [provision] known to the funding authorities." (reviewer).

"Risk assessments for care home placements are needed where there are individuals with health care needs that need regular intervention. This may result in the need for additional specialist staffing to support care homes or alternative placements." (reviewer).

Deaths from asthma[58]

There were 51 deaths notified to the LeDeR programme with asthma included in Part I of the MCCD. Of these, 28 reviews had been completed before the end of December 2019.

All but one of those who died from asthma were aged 25 and over; the greatest number of deaths (n=24) was in the age 65 and over age group.

There was little difference in the gender, ethnicity or level of learning disabilities of those who died from asthma compared to overall deaths notified to the LeDeR programme.

There was little difference in the proportion of deaths from asthma by region, other than the North West had a smaller proportion of such deaths than other regions. The greatest number of deaths from asthma were in the Midlands (n=13) and the North East and Yorkshire (n=11), but these are also the regions with the greatest overall number of deaths notified.

The quality of care received by those who died of asthma

Here we consider indicators of the quality of care for the 28 completed reviews of deaths of adults.

Best practice provided

Fourteen of the 28 completed reviews described aspects of best practice. These

[58] Asthma is a common lung condition that causes occasional breathing difficulties. It affects people of all ages and often starts in childhood, although it can also develop for the first time in adults. There's currently no cure, but there are simple treatments that can help keep the symptoms under control. The main symptoms of asthma are a whistling sound when breathing (wheezing), breathlessness, a tight chest, which may feel like a band is tightening around it, and coughing. When symptoms temporarily get worse it is known as an asthma attack. In the majority of people, the provision of appropriate treatment should result in the condition being managed without the need for admission to hospital, and asthma should not be a cause of death.

mostly related to close monitoring, good coordination and communication across services and full record keeping.

> "Clear evidence of efforts made by the surgery to maintain communication with all parties including 'ringing back' and taking steps to ensure communication with mum." (reviewer).

Problematic aspects of the person's care
Five reviewers commented on a problematic aspect of the person's care, in relation to concerns about the death, delays in the person's care or treatment, problems with organisational systems and processes or gaps in service provision.

> "Simon's sister said that she felt the GP should have physically examined Simon …rather than dismissing his presentation." (reviewer).

Overall grading of the quality of care

Over half (15 of 28 reviews) considered that the person's care had met or exceeded good practice. Eleven reviews thought that the care fell short of current good practice in minor ways; none considered that care fell short of expected good practice with the potential to contribute to the cause of death.

Thematic analysis of completed reviews where asthma was a cause of death

Thematic analysis of the circumstances leading to the 28 completed reviews identified two key issues:

- Evidence of an increasing number of respiratory problems prior to death.
- Problems accessing healthcare.

Evidence of an increasing number of respiratory problems prior to death
There was evidence of a pattern of increased respiratory-related issues in the 12-month period leading to death for 14 out of the 28 completed cases. This included an increased number of visits to the GP concerning respiratory related concerns, repeated and/or an increasing rate of antibiotic prescriptions, admissions to hospital for respiratory disease, and observations of deterioration by those involved in the person's care. One person was described as having 'an almost constant chest infection'.

> "A series of hospital admissions started [18 months prior to death], when Max was admitted with a severe chest infection..." (reviewer).

As detailed earlier in this chapter, pneumonia was the most common cause of death for people with learning disabilities. The majority of those who had asthma also had pneumonia at some point in the recent past.

> [The year leading to her death] "Helen deteriorated further, with a run of chest infections that did not respond to treatment…[and] developed pneumonia…At that time…the team were advised to stop medication and commence end of life care." (reviewer).

Problematic access to healthcare
Good preventative care is important for managing asthma, but there appeared to be lack of engagement with asthma or other health checks or interventions for several of those who had died. Where it was stated that an asthma or learning disabilities annual health check had not taken place and why, the reviews noted non-compliance on the part of the individual/their carers or families, or an apparent lack of an invite from their GP.

Kim was 38 when she died. Kim had moderate learning disabilities and several comorbidities. It was reported that she did not like going to medical appointments:
"…if any procedures or interventions were attempted, they were very difficult to carry out. Therefore, the GP and practice nurses only attempted to carry out interventions that were clinically necessary. Mother does not remember Kim being invited to the surgery for anything other than medication reviews." (reviewer).

A person's unwillingness to engage in medical interventions was discussed in several of these reviews, whether this be attending routine appointments, annual health/asthma checks, or when needing emergency treatment. In some reviews there is reference to the capacity of the person to make the decision, but more often there is no mention of an assessment of capacity or decisions being made in a person's Best Interests as required by the Mental Capacity Act, nor of reasonable adjustments being made to support the person to attend appointments.

"GP notes in relation to an annual asthma review: 'Asthma annual review - unable to perform review due to disabilities…unable to perform spirometry…this lady should be seen in own home not brought into surgery'. There was no reference to this being arranged." (reviewer).

Summary of recommendations specific to asthma as a cause of death

There were no recommendations specific to asthma as a cause of death. Most recommendations were general in nature, referring to the provision of learning disability annual health checks, adherence to the Mental Capacity Act, and the need for better communication between those supporting the person.

"GP surgeries to ensure that all patients with learning disabilities are…added to the learning disabilities register." (reviewer).

"Clinicians should routinely make referrals for mental capacity assessments when there are concerns regarding an individual's capacity, before making Best Interest decisions. Health and social care practitioners must understand and take into account the Mental Capacity Act 2005 when working with people with learning disabilities." (reviewer).

Deaths from influenza (flu)[59]

There were 43 deaths notified to the LeDeR programme with influenza included in Part I of the MCCD.

Of the 43 deaths notified to the LeDeR programme, 25 reviews had been completed before the end of December 2019.

Ten of the deaths of people from influenza were of children aged 4-17 years of age; 13 were of adults aged 25-49 years and smaller numbers distributed across the other age groups.

A greater number of males (n=26) than females (n=17) died from influenza.

There was little difference in the ethnicity or level of learning disabilities of those who died from influenza compared to overall deaths notified to the LeDeR programme.

The greatest number of deaths from influenza were in the Midlands (n=11) and London (n=10).

The quality of care received by those who died from influenza

Best practice provided

Ten of the 20 completed reviews of adults described aspects of best practice. These mostly related to evidence of good quality multi-disciplinary working and communication between different agencies.

> "There was good interface between hospital staff and the care team." (reviewer).

Problematic aspects of the person's care

Eight comments were made in completed reviews about problematic aspects of the person's care, in relation to concerns raised about the death, delays in the person's care or treatment, problems with organisational systems or processes, or gaps in service provision. The problems reported included delays in investigations, problems with there being suitably trained carers to use suction, and the provision of the influenza vaccine.

> "Mrs Morris declined the annual influenza vaccine for her daughter in November. Celia would have been due her annual health review that month, where this could have been discussed and Celia's health reviewed. However, there is no evidence in the GP record if an appointment was offered, although annual health reviews were recorded as completed at the GP surgery for the 2 previous years." (reviewer).

Overall grading of the quality of care

Ten of the 20 completed reviews of deaths from influenza noted that the person's care had met or exceeded good practice. Eight reviewers thought that the care fell short of current good practice in minor ways. One person was considered to have received care that fell so far short

[59] Influenza (flu) is a common infectious illness caused by the influenza virus. It is usually spread by coughs and sneezes and touch. Symptoms can start quite suddenly with fever and body aches, symptoms of the common cold, and cough. Occasionally, flu can cause severe illness including pneumonia. The influenza vaccine is recommended by the World Health Organization for high-risk groups, such as pregnant women, children aged less than five years, the elderly, health care workers and people who have chronic illnesses. The Joint Committee on Vaccination and Immunisation in England advises that the national flu immunisation programme should include people with learning disabilities.

of good practice that it contributed to their death.

Thematic analysis of completed reviews where influenza was a cause of death

The completed reviews of deaths from influenza highlighted once again, issues related to:

- Assessing the capacity of a person to make informed decision about their own care.
- The absence of information in health and care records about reasonable adjustments.
- How people often missed out on preventative care, including annual health checks and flu vaccinations.

"The system notes do suggest that Zara was invited for an influenza injection each year with the premise that a health check would be completed, though they did not attend for this appointment. There is nothing to indicate if this was followed up in primary care." (reviewer).

"Marvyn was invited again on [date]. GP advises that records show that he did not like to be examined and this is confirmed by Marvyn's sister…[there was] no record of Marvyn ever having a flu vaccination…" (reviewer).

Summary of recommendations specific to influenza as a cause of death

The only recommendations specific to influenza as a cause of death was in relation to the need for reasonable adjustments to be made for people with learning disabilities when offered influenza vaccinations. Public Health England has already published information about supporting people with learning disabilities to access influenza vaccines[60]. It seems that this needs to be better publicised.

Other recommendations were in relation to general health care and are similar to those recommendations found elsewhere. These included the need for thorough record keeping, improved communication with people with learning disabilities and their families, and the provision of training.

"Consideration should be given to developing a quality assessment programme/tool
to assess the standards of annual health checks within GP services." (reviewer).

[60] https://www.gov.uk/government/publications/flu-vaccinations-for-people-with-learning-disabilities/flu-vaccinations-supporting-people-with-learning-disabilities

Deaths of children aged 4 - 17 years

As previously mentioned, the deaths of children with learning disabilities are reviewed as part of the statutory child death review process. LeDeR reviewers are encouraged to contribute to the review process as appropriate and the completed review document (Form C) is shared with the LeDeR programme.

The children aged 4-17 years

From 1st July 2016 to 31st December 2019, the deaths of 516 children aged 4-17 years of age were notified to the LeDeR programme. Of these, 246 reviews had been completed by the Child Death Review programme and shared with the LeDeR programme by the end of 2019.

The demographic profile of the children aged 4-17 years notified to the LeDeR programme was very different to that of adults.

We have already seen (Figure 3, Chapter 2) that of those who died in childhood, 43% were from BAME groups and from that group 46% had profound and multiple learning disabilities (Figure 4, Chapter 2).

Overall, 7% of the deaths notified to LeDeR were of children aged 4-17 years, whereas in the general population just 0.3%[61] of the population die between the ages of 5-19 years.

Table 21 shows the most common underlying causes of death of 389 children for whom we have a verified ICD-10 code for the causes of death.

Table 21: Underlying cause of death by ICD-10 chapter for children aged 4-17 years with learning disabilities, and data about children aged 5-14 years in the general population

	Children with learning disabilities aged 4-17 years (2016-2019) (n=389) %	General population aged 5-14 years (deaths registered in 2018)[62] (n=580) %
Nervous system	27%	9%
Diseases of the respiratory system	15%	10%
Congenital malformations and chromosomal abnormalities	13%	7%
Endocrine, nutritional and metabolic diseases	12%	5%
Infections	8%	<1%
Neoplasm (cancer)	5%	28%
Diseases of the circulatory system	4%	7%
Diseases of the digestive system	4%	2%
Other underlying causes of death	12%	32%

[61] https://www.nomisweb.co.uk

[62] From:https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables

Over a quarter (27%) of children had an underlying cause of death attributed to disorders of the nervous system (e.g. epilepsy, meningitis).

The next most frequently reported underlying causes were: diseases of the respiratory system (15%); congenital and chromosomal disorders (13%), and endocrine, nutritional and metabolic disorders (12%).

Indicators of the quality of care provided

The mandatory child death review process does not assess the quality of care provided to the child in the same way that the LeDeR programme does. Some reviews of the deaths of children do have an additional LeDeR review, however this was not commonplace.

Here we consider the indicators of the quality of care for completed reviews of the deaths of children for which the information was available.

Examples of best practice provided[63]

A small proportion (6%; 12 of 200 reviews completed by the Child Death Review process) noted some best practice. Examples of best practice specifically in relation to children included:

- Good care coordination between different agencies and specialities.
- Excellent end-of-life care.
- The provision of person-centred care that was adjusted as the child's needs changed.

"There was excellent multi-agency working including medical, palliative and social care professionals to track for a range of different outcomes for Nat." (reviewer).

"The clinical records included several entries that captured the voice, wishes and feelings of Lilly." (reviewer).

"Acute paediatricians undertook 'outpatient appointments' at home to minimise the disruption to Frankie's care and routine." (reviewer).

Problematic aspects of care provided

Many issues were raised about the care provided to children and their families. The most frequently reported appeared to be in relation to:

- Delays in responding to signs of illness in the child or investigating illness.
- Poor quality multi-disciplinary working.
- Poor advanced care planning.
- Problems with the direct provision of care.

[Parents] "expressed their devastation at why their son was not investigated earlier for any condition that could have caused his signs and symptoms…it seemed Sandesh was never actively investigated, and that he got passed from pillar to post." (child death review panel).

"Will had complex multi-organ problems and was managed by six different specialist teams (general paediatric, gastroenterology, endocrinology, haematology,

[63] Please note that this information has been extracted and coded from the Child Death Review forms where there is no specific question about best practice, unlike in the LeDeR review process. Comparison should not therefore be made between adults and children.

orthopaedics and neurology). The parents commented that they requested and were offered a multi-disciplinary team meeting, but this never happened." (child death review panel).

"An advance care plan existed but had not been updated to encompass his condition during his final illness." (child death review panel).

"The ventilator humidifier was often left to run dry." (child death review panel).

"Care package provision was inconsistent and at times not appropriate." (child death review panel).

Summary of recommendations specific to the deaths of children

A number of recommendations were made specific to children aged 4-17 years of age. These included:

- The need to assign a key worker to coordinate care and ensure all agencies involved are fully informed and involved where necessary.
- The importance of timely advanced care planning and end of life care planning, with regular review, and in consultation with the family, paid carers, services currently involved and palliative care services.
- Better planned and well-coordinated discharge from hospital, with appropriately resourced community support to be in place.
- Support and communication with families to be provided consistently throughout a child's life. In the event of a death this support should continue with the provision of timely information and bereavement support.

"Child Death Overview Panel to write to the clinical leads in each paediatric department within the acute trusts…to express the importance of advanced care planning which includes organ donation and DNACPR. This should be done with families early…and be regularly reviewed with the family." (child death review panel).

"Earlier intervention and consultation from palliative care teams is to be highlighted to all clinical teams. This will promote early parallel planning for rehabilitation and/or palliative care." (child death review panel).

"This child's death highlighted the need for more support and resources for the dying child in the community." (child death review panel).

"All information/documentation needs handed over correctly and communication between teams needs to be sufficient to initiate care properly." (child death review panel).

Deaths of young people aged 18-24 years

Previous studies have indicated concerns about the transition from children's services to adult services and that despite a wealth of policy and guidance these principles are often not reflected in practice. The LeDeR programme selected this as a priority theme in recognition of such issues.

The people aged 18-24 years

From 1st July 2016 to 31st December 2019, the deaths of 306 young people aged 18-24 years of age were notified to the LeDeR programme. Of these, 113 reviews had been completed by the end of 2019.

The demographic profile of the young people aged 18-24 notified to the LeDeR programme was very different to that of adults aged 25 years and over, and more similar to children whose deaths were notified to the programme.

We have already seen (Figure 3, Chapter 2) that over a quarter (29%) of those aged 18-24 when they died were from BAME groups, and that 37% had profound and multiple learning disabilities (Figure 4, Chapter 2).

Overall, 4% of the deaths notified to LeDeR were of young people aged 18-24 years, whereas in the general population just 0.3% of the population die at these ages (Figure 6, Chapter 3).

Table 22 indicates the most common underlying causes of death of 241 young people aged 18-24 years for whom we have a verified ICD-10 code for the causes of death, compared to deaths of young people aged 15-24 years in the general population.

As Table 22 shows, the underlying cause of death for young people aged 18-24 with learning disabilities has a different profile than for young people in the general population.

A far greater proportion of young people aged 18-24 years with learning disabilities died from disorders of the nervous system (e.g. epilepsy, meningitis), respiratory system (e.g. pneumonia), and congenital malformations and chromosomal abnormalities, compared to young people in the general population.

Efforts to improve the longevity of young people with learning disabilities should focus on improving the treatment of epilepsy and pneumonia, including aspiration pneumonia.

Table 22: Underlying cause of death by ICD-10 chapter for young people aged 18-24 years with learning disabilities, and data about young people aged 15-24 years in the general population		
	People with learning disabilities aged 18-24 years (2016-2019) (n=241) %	**People in general population aged 15-24 years (deaths registered in 2017)[64] (n=1,978) %**
Nervous system	34%	7%
Diseases of the respiratory system	17%	4%
Congenital malformations and chromosomal abnormalities	13%	3%
Diseases of the digestive system	8%	2%
Diseases of the circulatory system	7%	7%
Endocrine, nutritional and metabolic diseases	5%	7%
Neoplasm (cancer)	5%	11%
Other underlying causes of death	11%	59%

Indicators of the quality of care provided

Here we consider the indicators of the quality of care for the 113 completed reviews of deaths of young people aged 18-24 years.

Examples of best practice provided

Over half (51%) of reviews noted some best practice. Examples of best practice specifically in relation to young people at transition included:

- Communication and coordination between children's and adults' services.
- The holistic provision of care, taking all of the young person's needs into account.

"Speech therapist in hospital contacted speech and language therapist from children's service who had worked with him at school for support and advice…as Naveed's needs different to adult acute patients with a typical dysphagia." (reviewer).

Problematic aspects of care provided

Of the 113 completed reviews, 18% noted that concerns had been raised about the death. Concerns were mainly in relation to:

- The quality of care received by the young person.
- Families not being listened to.
- The actual cause of death.

"Parents have expressed concerns that he was not fully reviewed by the GP the day before his death as his vital signs were not checked. They also feel that staff in the hospital did not listen to them when they were telling them that Harry was unwell and that how he was presenting was not usual for him. They feel that they saw Harry's learning disability before they assessed his physical health." (reviewer).

Delays in the person's care or treatment that adversely affected their health were reported in 12% of completed reviews. Delays were most commonly reported in:

[64] From: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables%20%20

- The identification and treatment of a person's illness.
- Providing an appropriate placement for the young person.

> "His treatment was delayed for over a year when he was discharged from children's services…which will clearly have adversely affected his health." (reviewer).

Problems with organisational systems and processes that led to a poor standard of care were reported in 17% of completed reviews. Such problems were mostly in relation to:

- Poor assessment processes.
- The transition from children's to adults' services, with the resulting fragmenting of a coordinated approach to care.
- Lack of clarity about decision-making.

> "The transition from children's to adult services was less than satisfactory for Molly and her family, who felt that they had to fight every step of the way for her. They had a good transitions social worker from [county A], [but this person and their replacement both moved on]. They were told to ring the duty worker if they had any problems. This left them feeling that there was no coordination of services for Molly … Some of Molly's services came from [county A] (education, social care) but health was largely from [county B] and the dietician was from [county A]." (reviewer).

Gaps in service provision that may have contributed to the person's death were reported in 11% of completed reviews. Most gaps described were in relation to:

- The provision of short breaks for the young person.
- A small number were in relation to the provision of care and appropriate support at transition to adult services.

> "The gap in the provision of care and treatment between leaving children's services …and finding appropriate adult health services …meant that his condition worsened considerably. This was a gap in service provision that may have contributed to his death." (reviewer).

Overall grading of the quality of care

Over half (56%) of the completed reviews of deaths of people aged 18-24 years noted that the person's care had met or exceeded good practice. A further 26% of reviewers thought that the care fell short of current good practice in minor ways. Fifteen young people were considered to have received care that fell so far short of good practice that it had the potential to cause them harm or it contributed to their death.

Summary of recommendations specific to deaths of people aged 18-24 years

A number of recommendations were made specific to the 18-24-year-old age group. These were mostly in relation to:

- The need for improved communication between children's and adults' services.
- To audit multi-agency involvement in transition planning for children and young people, and to take action accordingly.
- To review processes and documentation for undertaking MCA assessments in young people 16 years and over to ensure they correspond to the legislative requirements.
- To improve communication with families.

Panel comments

The Priority Theme Review aspect of the LeDeR programme from 2016-2018 examined the deaths of a subset of people in more detail. One of the priority themes was the deaths of young people aged 18-24 years.

Until September 2018, deaths of young people aged 18-24 years were expected to receive an initial and a multiagency review. The completed review documentation was then sent to a multi-agency panel (of health and social care professionals and family members) and a self-advocate panel (of people with learning disabilities).

After reviewing the completed reports of deaths, panel members commented on a number of issues that they felt could strengthen local recommendations. These were largely in relation to:

- Transition planning and the decision-making process once a young person becomes 16 years of age and is subject to the Mental Capacity Act.

"A theme is being identified that transition from child to adult care is a period of risk." (priority theme panel member).

"A named care coordinator would be beneficial for young adults requiring support from a number of different NHS Trusts." (priority theme panel member).

"Children's services should be trained regarding their role and responsibilities in the application of the Mental Capacity Act for young people aged 16 and above." (priority theme panel member).

Deaths of people aged 75 years and over at the time of their death

It is instructive to learn from the lives of those who lived beyond the median age at death. The LeDeR programme did not initially include the deaths of people with learning disabilities aged 75 years and over, although some reviews of people this age did take place. This was changed from 1st April 2017 with the introduction of the national guidance 'Learning from Deaths'[65].

Here we focus on the deaths of those aged 75 and over whose deaths were notified to the LeDeR programme. Most of these would have been notified from 1st April 2017 – 31st December 2019.

The people aged 75 years and over at the time of their death

The deaths of 983 people aged 75 and over were notified to the LeDeR programme. Of these, 418 reviews had been completed by the end of 2019.

Overall, 15% of the deaths notified to LeDeR were of people aged 75 years and over, whereas 68% of the general population die at these ages[66].

The demographic profile of those aged 75 years and over notified to the LeDeR programme was different to that of other adults in that they were less likely to be from BAME groups (3% compared to 10% of all deaths notified) and more likely to have mild (41%) or moderate (39%) learning disabilities compared to all deaths notified (30% and 34% respectively).

Over half (56%) of those aged 75 and over were male; similar to 58% of males whose deaths were notified. In the general population of England and Wales, the proportion of females exceeds that of males at ages 75 and over[67].
There was no difference in the proportion of people dying at age 75 and over by geographical region.

A review of the personal histories of those who lived a long life, where such information is available, suggests a number of commonalities as described below.

Moving to an institutional setting at an early age.
Many had lived in institutions for many years, often since a very young age, before being moved to community setting as a result of changes in national policy.

Some reviewers noted distressing circumstances within these settings: one reviewer wrote "it was horrible and people smashed windows and it was dirty"; another reviewer noted: "*Helen used to tell staff that people suffered very harsh treatment there and that it was a rough life".*

Others reported that the experiences in the institution had influenced the person's character, behaviour or interests in subsequent years, such as obsessions

[65] https://www.england.nhs.uk/publication/national-guidance-on-learning-from-deaths/
[66] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables
[67] https://www.gov.uk/government/publications/death-in-people-aged-75-years-and-older-in-england-in-2017/death-in-people-aged-75-years-and-older-in-england-in-2017

about particular objects, not wanting to be alone, repetitive behavioural patterns, displaying behavioural challenges, or having an interest in nature.

Many people were reported to have made strong friendships in such institutions, which in some cases lasted for many years after leaving.

Lifelong family contact, which provided consistency, support and advocacy for the person.

Whether a person had or had not lived in an institution in their early years, many were reported to have had strong support from their families throughout the duration of their lives.

When parents had died, contact was usually maintained with siblings, nephews or nieces. Relatives provided considerable consistency in people's lives and seemed to act as strong advocates on many occasions by taking a proactive role in obtaining the right care for their relative.

The person having 'character', feistiness or strong, sustaining interests, often developed in one's youth.

Many of those who died at age 75 or older were described vividly, with a strong sense of the person having character and/or strong sustaining interests which had been encouraged by those supporting them.

Many were described as knowing their own mind and not being afraid to speak up for themselves.

Some were supported to have pets, to play musical instruments or do knitting or handicrafts; some had very specific interests, such as different cultures or costumes, everyday items such as clocks, trains or engines, or wearing particular colours or items of clothing.

The person being sociable, having lasting friendships and wanting to engage with others.

Several of those who had died at aged 75 and over had been married in the past and seemed to have enjoyed the sense of belonging and responsibility this brought. Some had had children, but few were still in touch with their own children.

Many were described as having strong friendships, irrespective of whether they were married; friendships were often initiated at day services and the friends were sometimes supported to move into the same residential setting together in later years.

Many descriptions of people mention that in younger days the person had been very sociable, preferring to be 'out and about' and well-known in their local communities.

A sense of purpose in their lives.

It was often the case that the 'pen portraits' of those who died aged 75 and over suggested that they had experienced a sense of purpose in their lives, through work, contributing to their local community, supporting family or friends, or otherwise having a 'role' in life.

For most, this appeared to have been whilst still living with their family, with the family fostering opportunities for them to become involved in activities that provided a sense of status or engagement with the community. One person was described as being responsible for 'weighing out sweets'; another helped his sister 'sweep up cuttings' in her work as a machinist; others sold newspapers, enjoyed being a bingo caller, did the household shopping or cared for pets.

The impact of a single event on the person's health and wellbeing.
For many people, the decline in their health and wellbeing had occurred over a number of years, with increasing frailty and multi-morbidity.

There were, however, people for whom a single event or illness precipitated such a significant change in their wellbeing that they never fully recovered prior to their death. For some, these were events such as hate crime that affected them emotionally, causing them to become deskilled or afraid of leaving their home; for others it was a medical illness that had led the person to requiring increased assistance with personal care or mobility, and being forced to move home and to new care arrangements to which they may not have responded well. It appears that where this was the case, the potential knock-on effects of the signal event had not been fully considered.

It seems that those who lived to ages 75 and over enjoyed a set of circumstances in the past that may not be common practice for some people with learning disabilities today, particularly feeling included and belonging in one's community; being supported to have a range of strong friendships; and having a sense of purpose in one's life[68].

The extracts (below) from the pen portraits of people who died illustrate many of the commonalities described above.

"Charles lived with his mother for over 70 years until her health deteriorated and both she and Charles went to [a residential care home]. Whilst there, Charles became great friends with another resident who remained a close friend until his death. …Charles moved to the care home on his mother's death. Charles had a close relationship with his family, and he saw his brother two to three times a week. He had a telephone in his room with his brother's number on speed dial and called him every night at 7pm. Charles was close to his niece…and had a wonderful relationship with his great nephew and niece.
Charles liked watches. He could recognise the hours and would often tap his watch face to indicate that it was time to go or do something different.
Charles was a very polite and sociable person who liked people. He had lots of friends…He enjoyed going out for a walk and did so regularly with carers and his brother. He also liked to go to the theatre to see shows and used to enjoy going on coach day trips. He went to cricket matches with his brother. He also enjoyed gardening and growing tomatoes…"

"Douglas could be a very sociable man when he chose to be. He 'loved a bit of a show' and enjoyed talking about his life working on his brother's farm. From talking to those who knew Doug it is clear that he was a man who very much knew his own mind and was not afraid to stand his ground if he didn't want to do something. Doug's interest in farming grew from living on a farm and working with his brother in the milking parlour. In later life Doug enjoyed reading magazines about tractors, steam engines and small holdings. Doug

[68] See: Malli MA., Sams L., Forrester-Jones, R., Murphy G., Henwood M. (2018) Austerity and the lives of people with learning disabilities. A thematic synthesis of current literature, Disability & Society, 33:9, 1412-1435.

had a large family who visited him regularly. Doug kept regular contact with most of his family, in particular his sister and her husband."

"Irene …lived in an institution from quite a young age. She met a friend at her school …they remained best friends for the rest of their lives and moved out of the hospital as adults and into supported accommodation together… Irene was married to Stewart for 20 years…She had a very active life up until 2014 when her physical health deteriorated… Irene was able to turn her hand to anything crafty, knitting, sewing, crochet and tapestry."

Table 23 indicates the most common underlying causes of death of 853 people aged 75 and over for whom we have a verified ICD-10 code for the causes of death, compared to deaths of people aged 75 and over in the general population.

As this shows, people with learning disabilities aged 75 years and over more frequently died of respiratory disease and less frequently died of cancer than people in the general population of the same age group.

Table 23: Underlying cause of death by ICD-10 chapter for people aged 75 and over with learning disabilities, and data about people aged 75 and over in the general population of England (2018)

	People with learning disabilities aged 75 and over (2016-2019) (n=853) %	People in general population aged 75 and over (deaths registered in 2018) (n=345,192)[69] %
Diseases of the respiratory system	29%	16%
Diseases of the circulatory system	21%	26%
Neoplasm (cancer)	13%	22%
Mental behavioural and neurodevelopmental	12%	13%
Diseases of the digestive system	8%	4%
Nervous system	6%	8%
Other underlying causes of death	11%	11%

Indicators of the quality of care provided

Here we consider the indicators of the quality of care for the 418 completed reviews of deaths of people aged 75 and over.

Examples of best practice provided

Almost half (47%) of reviewers noted some best practice. Examples of best practice that were specific to deaths of people aged 75 and over included:

- Adapting the provision of care as a person got older and their needs changed.
- The provision of consistent support by familiar people over a long period of time.
- The provision of well-coordinated, holistic care.

[69] Calculated from: https://www.nomisweb.co.uk

"Winston's day service was very accommodating and flexible as his health deteriorated. They adapted Winston's activities around what he could and could not manage even if he just wanted to attend for a short while. When Winston looked tired or said that he had enough for the day they were proactive in arranging for Winston to go home." (reviewer).

"It was clear that Henry's health was beginning to fail as he got older. The care team took account of this in terms of the support that was provided. He was well known to staff as he had been in the service provision for over 30 years." (reviewer).

"There was excellent communication between carers and [Trust staff] and consideration of how to manage Alice's increasing fragility which required hospital admissions and investigations." (reviewer).

Problematic aspects of care provided

Of the completed reviews, a small proportion noted problematic aspects of care: 6% noted that concerns had been raised about the death; 8% had delays in the person's care or treatment that adversely affected their health; 10% had problems with organisational systems and processes that led to a poor standard of care; and 3% gaps in service provision that may have contributed to the person's death.

Very few of these problematic aspects of care appeared to be related specifically to the person's age; rather they were aspects of care that could have affected anyone.

Overall grading of the quality of care

Over half (57%) of the completed reviews of deaths of people aged 75 and over noted that the person's care had met or exceeded good practice. A further 32% of reviews reported that the care fell short of current good practice in minor ways. Fewer than ten people aged 75 and over were considered to have received care that fell so far short of good practice that it had the potential to cause them harm or it contributed to their death.

Recommendations specific to people aged 75 and over

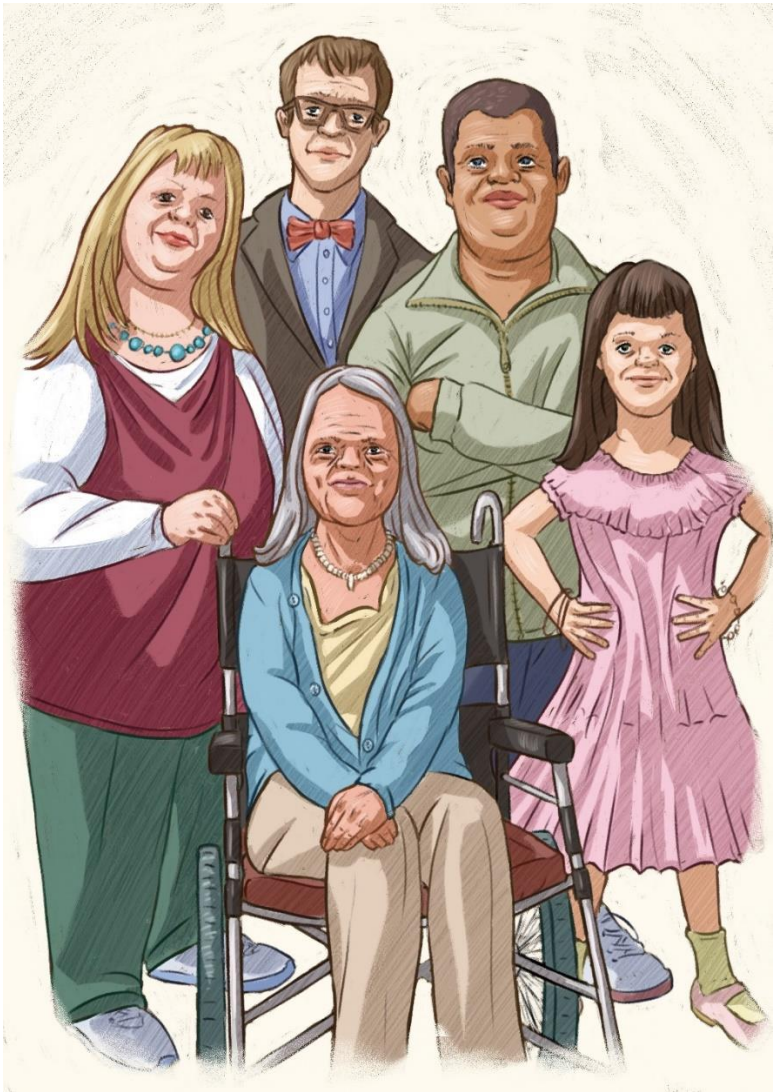
A number of recommendations were made specifically in relation to the care of people aged 75 and over. These included the need for:

- Greater attention to forward planning as people age, including appropriate accommodation options.
- Greater recognition about how a person's experiences at younger ages can impact on their life in later years.
- The provision of training about the physical, psychological and social needs of older people with learning disabilities, particularly for staff working in supported living settings and generic care or nursing homes.
- A holistic approach that integrates elderly assessment checks and learning disabilities annual health checks, and results in joint care planning and the sharing of information across the agencies that support the individual.

"Care staff should receive training on the common changes in health needs for people with a learning disability as they get older including increasing risk of dysphagia and aspiration." (reviewer).

Chapter 6

Summary and recommendations[70]



[70] The recommendations were developed prior to the COVID-19 pandemic. We acknowledge that due to the pandemic, they may not be able to be acted on immediately.

This report presents findings from reviews of the deaths of people with learning disabilities notified to the LeDeR programme from 1st July 2016 – 31st December 2019, with a focus on information about deaths reviewed during the last calendar year (1st January – 31st December 2019).

We discussed the findings included in the report with three consultation groups: one of self-advocates, and two of professionals and family members. Together, we prioritised the key issues raised and discussed potential recommendations. We would like to thank those who helped us in this way.

What is working well, that we could do more of?

First, we consider the best practice identified in completed reviews. As has already been mentioned, everyone should expect to receive care that meets good practice, but this was the case in just over a half (56%) of reviews of deaths of adults with learning disabilities completed in 2019.

Many reviewers reporting best practice commented on standards of care that anyone should expect to receive. However, there were some reviews where care seemed to be particularly good, from which lessons could be learned about what worked well. Table 24 summarises aspects of best practice most frequently identified in completed reviews in 2019.

Table 24: Best practice most frequently identified in completed reviews in 2019

Best practice most frequently identified	Care met/exceeded best practice	Findings of multi-agency review	Deaths from pneumonia	Deaths from sepsis	Deaths from epilepsy	Deaths from DVT/PE	Deaths from diabetes	Deaths from asthma	Deaths from influenza	Deaths from BAME groups	Deaths of children	Deaths aged 18-24 years	Deaths aged 75+ years
Good quality multi-disciplinary working		✓		✓		✓	✓	✓	✓		✓	✓	✓
Holistic person-centred care	✓	✓				✓	✓					✓	✓
Regular proactive reviews of health condition, needs and risk assessments	✓	✓	✓		✓			✓					
Well-coordinated care	✓	✓	✓								✓		✓
Good communication with families		✓		✓								✓	
Good quality end-of-life care		✓		✓							✓		
Reasonable adjustments to care		✓					✓						
Full and accurate record keeping		✓						✓					

Overall, the key to providing good quality support appeared to be the provision of effective multi-disciplinary working that had the person and their family at its centre, was well-coordinated by a named person, and took a proactive approach to meeting the health and care needs of the individual.

We need therefore to ensure that these aspects of care are more firmly embedded in systems and processes.

Key issues for service improvement identified in completed reviews

Table 25 summarises the most frequently identified issues raised in the completed reviews of deaths in 2019.

We discussed these issues with some consultation groups to prioritise those for which additional recommendations may be required. Many of these issues are similar to those raised in previous years by the LeDeR programme and in a range of other reports relating to premature deaths of people with learning disabilities.

Those that were most frequently represented were:

- Delays in the diagnosis and treatment of illness.
- Poor care coordination and communication between agencies.
- Omissions in care or the provision of substandard care.
- Poor application of the Mental Capacity Act.
- Lack of timely referral to specialists, including learning disability services and neurologists.

Recommendations to support service improvement

Addressing inequalities

Deaths of people from BAME communities

Recommendation 1.
Ensure continued focus on BAME deaths of all adults and children within, but not limited to, the LeDeR programme.
(Audience: NHSE, DHSC).

A clear pattern is now emerging from national data about deaths of people with learning disabilities showing that people from BAME communities are disproportionately likely to have profound and multiple learning disabilities and to die in childhood or early adulthood.

A recent systematic review[71] of what we know about the health and health care of children and adults with learning disabilities from BAME communities in the UK suggested that people with learning disabilities from BAME groups were more likely than others to face barriers in accessing services, less likely to receive specialist services, and more likely to have poor knowledge about those services available to them. It concluded that little is known about their health status and that they are likely to experience barriers to accessing specialist learning disability services.

[71] https://onlinelibrary.wiley.com/doi/full/10.1111/jar.12630

Table 25: Summary of key issues most frequently identified in completed reviews in 2019																		
Issues most frequently identified	**Overall care graded as 6**	**Overall care graded as 5**	**Concerns noted about care**	**Delays in the provision of care**	**Problems with org systems/processes**	**Gaps in the provision of care**	**Findings of multi-agency review**	**Deaths from pneumonia**	**Deaths from sepsis**	**Deaths from epilepsy**	**Deaths from DVT/PE**	**Deaths from diabetes**	**Deaths from asthma**	**Deaths from influenza**	**Deaths from BAME groups**	**Deaths of children**	**Deaths aged 18-24 years**	**Deaths aged 75+ years**
Delays in the diagnosis and treatment of illness	✓	✓	✓	✓			✓	✓	✓				✓	✓	✓	✓	✓	
Poor care coordination and communication between agencies	✓	✓			✓	✓	✓	✓	✓		✓				✓	✓	✓	
Omissions in care or the provision of substandard care	✓	✓	✓				✓	✓	✓	✓	✓	✓		✓		✓		
Application of the Mental Capacity Act		✓		✓			✓	✓	✓	✓							✓	
Lack of timely referral to specialists, including learning disability services					✓			✓	✓	✓	✓							
Out-of-date assessments, care plans or policies						✓		✓		✓		✓					✓	
Lack of holistic and proactive care	✓	✓						✓		✓								✓
Training needs of carers					✓			✓		✓		✓		✓				
Delays in escalating concerns									✓	✓	✓	✓						
Poor engagement with families		✓									✓				✓		✓	
Poor hospital discharge arrangements			✓								✓	✓						
Lack of attention to physical health needs	✓								✓		✓							

The LeDeR programme does not yet have sufficiently good epidemiological evidence about the contributory factors leading to deaths of people from BAME groups, as the number of deaths is comparatively small when broken down by different age groups and across the range of different ethnic minority groups.

We recommend that a continued focus on the deaths of all adults and children from BAME groups reported to the LeDeR programme is required, as well as in the Child Death Review programme and Learning from Deaths guidance.

In addition, consideration should be given to linking LeDeR data with other national data sets relevant to the health of people with learning disabilities, such as the General Practice Extraction Service and the Hospital Episode Statistics data, in order to systematically and more fully investigate the experiences of people from BAME groups and be assured that any health inequalities are addressed.

Deaths of people with learning disabilities reported to the coroner

Recommendation 2
For the DHSC to work with the Chief Coroner to identify the proportion of deaths of people with learning disabilities (and possibly other protected characteristics) referred to a coroner in England and Wales. (Audience: DHSC, Chief Coroner).

We have reported that deaths of people with learning disabilities appeared to have been reported to a coroner far less frequently than people in the general population (32% of deaths of adults with learning disabilities in England compared with 41% of adults and children in the general population of England and Wales).

Direct comparison has not been possible because child death reviews do not routinely include a standard question about whether the death was reported to a coroner or not; hence we do not have full data about deaths of children with learning disabilities. Coroners statistics do not present data for adults and children separately.

It may, of course, be the case that LeDeR reviewers were not always aware whether a death was reported to a coroner or not; there is some regional variation between coroners as to what they consider constitutes a substantive "reported death" (and are therefore reported in their statistics) where little or no action is required on their part and no post-mortem or inquest is held[72].
However, such a difference in the proportion of deaths reported was first identified in CIPOLD (2013) and has been a consistent finding in LeDeR programme annual reports since.

The public sector Equality Duty[73], part of the Equality Act, requires public bodies to consider all individuals when delivering services, and that public bodies have due regard to the need to eliminate discrimination and advance equality of opportunity. The Ministry of Justice publishes some data about deaths reported to coroners by age and gender but not by other protected characteristics

[72] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/800864/Coroners_statistics_2018_supporting_guide.pdf

[73] http://www.legislation.gov.uk/ukpga/2010/15/section/149

as defined by the Equality Act 2010[74], such as learning disabilities. Our concern here is the absence of reporting specifically in relation to learning disabilities, but other protected characteristics may also be relevant.

Our recommendation, therefore, is for the DHSC to work with the Chief Coroner and request an audit of the proportion of deaths of people with learning disabilities (as a group of people with protected characteristics) referred to a coroner in England and Wales. If this information is not available, a specific audit programme should be established to gather it. Once the data is available, it should be reported on by the Ministry of Justice, and any necessary actions taken to eliminate discrimination.

Adherence to the Mental Capacity Act

Recommendation 3
(Repeated from the House of Lords Select Committee on the Mental Capacity Act 2005).

The standards against which the Care Quality Commission inspects should explicitly incorporate compliance with the Mental Capacity Act as a core requirement that must be met by all health and social care providers. (Audience: Care Quality Commission).

Understanding of, and adherence to, the Mental Capacity Act continues to be a significant problem in the care of people with learning disabilities. Issues related to the understanding of, and adherence to, the Act were raised in CIPOLD, in the House of Lords Select Committee on the Mental Capacity Act 2005, and in previous LeDeR annual reports[75]. There has been no shortage of policy or practice guidance, either promised or delivered, yet adherence to the requirements of the Act remains patchy, often with significant impact on the lives of those about whom decisions are made.

In addition, we have seen in Chapter 5 that family involvement in the Best Interests decision-making process requires improvement.

In our second annual report we recommended that 'Local services strengthen their governance in relation to adherence to the MCA, and provide training and audit of compliance 'on the ground' so that professionals fully appreciate the requirements of the Act in relation to their own role.'

The need for this has not reduced. Training about the Mental Capacity Act should be included in the new Oliver McGowen training for all staff but training alone is unlikely to support the progress that is needed.
We recommend that the Care Quality Commission should establish and determine within all regulated services that individual staff are aware of their responsibilities and duties under the Mental Capacity Act.

The wording of this recommendation is that of the House of Lords Select Committee on the Mental Capacity Act 2005[76]: that the standards against which the Care Quality Commission inspects should explicitly incorporate compliance with the Mental Capacity Act as a core

[74] http://www.legislation.gov.uk/ukpga/2010/15/contents
[75] See Appendix 7 for a summary of recommendations made and government responses to these.
[76] https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf

requirement that must be met by all health and care providers.

The provision of care

Coordination of care

Recommendation 4
Consider the recommendations from the 'Best practice in care coordination for people with a learning disability and long term conditions'[77] (March 2019) report and:

- Establish and agree a programme of work to implement the recommendations.
- Liaise with NIHR regarding the importance of commissioning a programme of work that develops, pilots and evaluates different models of care coordination for adults and children with learning disabilities.

(Audience: DHSC and NIHR)

The impact of poor care coordination on premature deaths of people with learning disabilities has repeatedly been highlighted since the Michael Report (2008) 'Healthcare for All'[78]. CIPOLD (2013) recommended a named healthcare coordinator be allocated to people with complex or multiple health needs, or two or more long-term conditions. The two previous LeDeR annual reports have also recommended strengthening care coordination to enhance person centred care and support planning.

We acknowledge that the need for appropriate care coordination is one of the core principles that underpins the ongoing transformation of care and support services in this country, both for adults generally and more specifically for people with learning disabilities and long-term conditions. To-date, however, the government response to recommendations about introducing care coordination for people with learning disabilities and long-term health conditions has been insufficient[79], as evidenced by considerable ongoing concerns about its absence as a potentially avoidable contributory factor leading to deaths.

The report from the Institute of Public Care (IPC) at Oxford Brooks University, written for the DHSC called 'Best Practice on Care Coordination for People with a Learning Disability and Long-Term Conditions' was published on the IPC website in March 2019[80]. DHSC have committed to publishing a revised version of the report by summer 2020[81], including additional case studies, as set out in the response to the third LeDeR report in February 2020.

The IPC report identified six key characteristics of successful care coordination[82]. These include:

- A single point of access to a range of services, so that the person only needs to tell their story once.
- Integrated assessment and planning, with all relevant professionals feeding in and listening to the aspirations of the person as the starting point.

[77] https://ipc.brookes.ac.uk/publications/pdf/Care_coordination_for_people_with_LD_%26_long_term_conditions.pdf
[78] https://webarchive.nationalarchives.gov.uk/20130105064250/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_09925
[79] See Appendix 7 for a summary of recommendations made and government responses to these.
[80] https://ipc.brookes.ac.uk/publications/pdf/Care_coordination_for_people_with_LD_%26_long_term_conditions.pdf
[81] https://www.gov.uk/government/publications/leder-third-annual-programme-report-government-response
[82] https://ipc.brookes.ac.uk/publications/pdf/Care_coordination_for_people_with_LD_%26_long_term_conditions.pdf

- A flexible approach which means pathways and services are coordinated around the needs and wishes of the person.
- Key workers/navigators to help coordinate individual care packages as well as influence mainstream services to improve accessibility.
- Learning and development initiatives that define key competences to enable people who have roles that include care coordination to perform better.
- Whole system approaches that enable joined up responses across health, social care, housing, employment and beyond through shared strategies, plans and budgets that tackle some of the wider determinants of poor health including poverty, poor housing conditions, unemployment.

Using the review findings, we recommend that the Department work with the National Institute of Health Research to commission a programme of work that develops, pilots and evaluates different models of care coordination for adults and children with learning disabilities, based on the key characteristics of care coordination as described in the Institute of Public Care report.

Delays in the provision of healthcare

Recommendation 5
Adapt (and then adopt) the National Early Warning Score 2 regionally, such as the Restore2 in Wessex[83], to ensure it captures baseline and soft signs of acute deterioration in physical health for people with learning disabilities by:
- Involving people with learning disabilities, their families and professional organisations.
- Disseminating for use across acute, primary and community settings.

(Audience: NHSEI, professional organisations and people with learning disabilities).

Recommendation 6
Consider developing, piloting and introducing:
- Specialist physicians for people with learning disabilities who would work within the specialist multi-disciplinary teams.
- A Diploma in Learning Disabilities Medicine.
- Making 'learning disabilities' a physician speciality of the Royal College of Physicians.

(Audience: DHSC and the Royal College of Physicians).

There two key reasons for delays in the provision of healthcare for people with learning disabilities:
- Delays in recognising acute deterioration of health in a person. A failure to recognise, escalate and respond appropriately can cause preventable harm.
- Difficulties that people had in accessing appropriate healthcare in a timely way – largely but not solely due to a lack of recognition and understanding of the person's needs, fragmentation of their care, and insufficient attention to any reasonable adjustments they may require.

Both issues have been raised in previous reports about premature deaths of people with learning disabilities and we are disappointed that these remain such strong themes in the data for 2019.

[83] https://wessexahsn.org.uk/projects/329/restore2

Previous recommendations have been for DHSC to prioritise a programme of work to recognise deterioration of health or early signs of illness in people with learning disabilities, and for the provision of reasonable adjustments to be made. In 2020, the DHSC responded to the third LeDeR annual report noting that NHS England would be publishing an Action from Learning report to demonstrate the range of changes that have taken place as a result of learning from LeDeR reviews.

Given the scale of the problems still apparent, and their close relationship to premature deaths, we recommend two policy level changes. In our view, local initiatives are not sufficiently robust in themselves to address the magnitude of the problem.

Firstly, in relation to recognising acute deterioration in the health of a person with learning disabilities, we recommend that NHS England and Improvement work with the appropriate professional bodies, including the Royal College of Physicians and Academic Health Science Networks, and people with learning disabilities and their families, to adapt the National Early Warning Score (NEWS2) regionally, such as the Restore2 in Wessex, to make it more appropriate for people with learning disabilities. Some people with learning disabilities can be unable to tolerate full physiological observations without prior desensitisation. For others, the interpretation of the NEWS2 score obtained against what is 'normal' for that person can be problematic. The adapted version should be then be introduced across acute, primary and community settings.

Second is the issue of people with learning disabilities having difficulty accessing healthcare in a timely way. This appears to have been an intractable issue to date that is closely related to premature deaths and requires clear national guidance and commitment.

Hull Clinical Commissioning Group planned to appoint a specialist learning disabilities physician to support adults with complex needs[84]. The initiative was introduced after the condition of a person improved dramatically with the input of a palliative care doctor trained in learning disabilities.

We recommend that the DHSC reviews the initiative in Hull, then considers developing, piloting and introducing specialist physicians for people with learning disabilities to work across the population of people with learning disabilities, in a similar way that paediatricians and geriatricians do with the youngest and oldest age groups.

At present, learning disability psychiatrists support the mental health of people with learning disabilities, but there is a significant gap in supporting the physical health of this population. The learning disability consultant would concentrate on supporting the physical needs of people for whom accessing appropriate mainstream services is the most difficult, taking a holistic approach and involving and coordinating a multi-disciplinary team. In addition, the DHSC to work with the Royal College of Physicians to develop and introduce a Diploma in Learning Disabilities Medicine, and to make 'learning disabilities' a physician speciality of the College.

[84] https://www.theguardian.com/society/2019/jul/24/specialist-doctor-learning-disability-save-lives

Priority areas of focus

Deaths from pneumonia and aspiration pneumonia

Recommendation 7
Consider the need for timely, NICE evidence-based guidance that is inclusive of prevention, diagnosis and management of aspiration pneumonia in adults and children. The outcome of such considerations should be shared with DHSC and NHSE.
(Audience: NICE, DHSC, NHSE).

Recommendation 8
RightCare to provide a toolkit to support systems to improve outcomes for adults and children at risk of aspiration pneumonia.
(Audience: NHSE).

Deaths from pneumonia and aspiration pneumonia continue to be of considerable concern and appear to be over-represented in avoidable medical causes of death. In all, 24% of deaths had bacterial pneumonia included in Part I of the MCCD and 16% of deaths had aspiration pneumonia recorded. The comparable proportions in our last annual report were 25% and 16%.

In our last annual report published in May 2019, we recommended the following: 'The Department of Health and Social Care, working with a range of agencies and people with learning disabilities and their families, to prioritise programmes of work to address key themes emerging from the LeDeR programme as potentially avoidable causes of death. The recommended priorities for 2019 include: i) recognising deteriorating health or early signs of illness in people with learning disabilities and ii) minimising the risks of pneumonia and aspiration pneumonia.'

In the DHSC response to the report published in February 2020[85], the action arising from this recommendation was noted as being:
'NHS England will publish another Action from Learning report to demonstrate the range of changes that have taken place as a result of the learning from LeDeR reviews. The next Action on Learning report will be published in late Spring 2020.'
In our view there is a degree of urgency to go further than this in addressing the high proportion of deaths from these potentially avoidable causes.

In 2013, when concern about the proportion of deaths from respiratory disease was raised by CIPOLD, the government confirmed that: 'NHS England will ensure that the National Clinical Director for Learning Disability will collaborate with the National Clinical Director for Respiratory Medicine to promote and support evidence-based implementation of best practice for prevention, management and treatment of respiratory conditions, including immunisation of people with learning disabilities who are at risk.'
We are not aware of any published outcomes from this work.

Our recommendations, therefore, are specific and focused, and targeted at the policy level change we need.
There is already a NICE guideline available for 'Pneumonia in adults: diagnosis and management' [CG191], but we have noted some variation in how aspiration pneumonia is identified and treated. Our

[85] See Appendix 7 for a summary of recommendations made and government responses to these.

own discussions with experts in the field and published literature suggest there may be dangers in both over- and under-reporting aspiration pneumonia, and that some treatment approaches, such as thickening fluids and prescribing Proton Pump Inhibitors could potentially have unhelpful effects if the diagnosis is not accurate[86,87]. At present there are no national clinical guidelines about the diagnosis and treatment of aspiration pneumonia. Our first recommendation is for NICE to consider in a timely way, the need for new NICE guidelines for the prevention, diagnosis and treatment of aspiration pneumonia that includes adults and children with learning disabilities. The outcome of such considerations should be shared with DHSC and NHSE.

We acknowledge that this will take time, *and* that time is of the essence. Our second recommendation is for RightCare[88] to provide a toolkit to support systems to make improvements in outcomes for adults and children at risk of aspiration pneumonia. This should include advice about preventative measures for those at risk of aspiration pneumonia, including postural support and dental care; early signs that a person's risk of aspiration is increasing; guidance about the use of feed thickeners; the standardisation of descriptions of liquid consistencies; and guidance on managing reflux.

Deaths from epilepsy

Recommendation 9
For safety of people with epilepsy to be prioritised. The forthcoming revision of the NICE Guideline 'Epilepsies in children, young people and adults' to include guidance on the safety of people with epilepsy, and safety measures to be verified in Care Quality Commission inspections.
Audience: DHSC, Care Quality Commission.

Epilepsy was the sixth most frequently recorded cause of death in people with learning disabilities in 2019 and 2018, and the second most frequently reported potentially treatable cause of death.

From the evidence we have from completed reviews of death, many of the basic safety measures for people with epilepsy did not appear to have been in place for all people with epilepsy. Such safety measures include:

- Completion of a seizure and SUDEP safety checklist and receiving regular risk assessments (e.g. an epilepsy self-monitoring tool[89]).
- Access to training about the condition (e.g. national guidance from the Epilepsy Nurses Association about the use of rescue medication[90]) for people with epilepsy and those who support them.
- Having an up-to-date epilepsy care plan and Summary Care Record.
- Having, as a minimum, an annual review of one's epilepsy.

[86] Wolter NE, Hernandez K, Irace AL, et al. A systematic process for weaning children with aspiration from thickened fluids. JAMA Otolaryngol Head Neck Surg. 2018;144(1):51–56.
[87] Eom CS, Jeon CY, Lim JW, Cho EG, Park SM, Lee KS. Use of acid-suppressive drugs and risk of pneumonia: a systematic review and meta-analysis. CMAJ 2011;183:3109.
[88] https://www.england.nhs.uk/rightcare/what-is-nhs-rightcare/
[89] See: https://sudep.org/epilepsy-self-monitor
[90] https://esna-online.org/

- Having easy access to an epilepsy specialist nurse who can be contacted between scheduled reviews.

Such basic safety measures are vital in helping to avoid premature death from the condition.

We recommend that there should be a renewed focus on the safety of people with learning disabilities and epilepsy that incorporates all relevant safety measures.

Consideration needs to be given to the recommendations in the recently launched RightCare Toolkit[91] which includes best practice for seizure surveillance and management, and the Royal College of Psychiatrists reports[92,93] on supporting people with learning disabilities and epilepsy. The forthcoming revision of the NICE Guideline 'Epilepsies in children, young people and adults' should include specific guidance on the safety of people with learning disabilities with epilepsy.
Additionally, use of epilepsy safety protocols in place, should be highlighted and reviewed in CQC inspections.

Deaths related to constipation

Recommendation 10
For a national clinical audit of adults and children admitted to hospital for a condition related to chronic constipation. The National Clinical Audit and Patient Outcomes Programme is one way this could happen.
(Audience: National Clinical Audit and Patient Outcomes Programme Partners Sub-group, NHSE).

Constipation is undoubtedly a significant problem for people with learning disabilities – 23% of completed reviews identified constipation as a long-term health problem and 33% reported that the person was usually prescribed laxatives. Considering constipation is a treatable condition, it has been of concern to hear about people whose deaths have been related to constipation.

The data available from completed reviews about deaths related to constipation will take time to analyse fully. In part, that is because constipation is rarely included as a cause of death in Part I of the MCCD. Some causes of death are described as being due to bowel ischaemia, intestinal blockage or volvulus, which appear to have chronic constipation as a contributory cause, but do not include it on the MCCD. More detailed information is required about these deaths to more accurately identify and assess the contribution of long-term chronic constipation.

We recommend that the provision of such information comes from a national clinical audit of adults and children admitted to hospital for a condition related to chronic constipation. National clinical audits collect and analyse data supplied by local clinicians to provide a national picture of care standards for that specific condition. By including data from people with learning disabilities and the general population, such an audit would focus on improving the prevention and treatment of constipation across different patient groups and ensuring that this entirely preventable cause of death is avoided.

[91] https://www.england.nhs.uk/rightcare/products/pathways/epilepsy-toolkit/
[92] https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr203.pdf?sfvrsn=c534ff08_2
[93] https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr206.pdf?sfvrsn=4db7a660_2

Final comments

"If your programme prevents the loss of one more vulnerable adult's life or ensures they are treated with empathy and dignity, you may use any information. It cannot bring back my son, but it can help others." (quote from a father).

We would like to conclude this report with the quote above from the father of a person whose death was reviewed by the LeDeR programme.

Let us just pause and think about it for a while. Here is a father allowing us to share his son's story so that other people with learning disabilities don't experience similar treatment. In the view of the report's authors, and the LeDeR programme steering group based at the University of Bristol, we need to ask ourselves how it can be we have so lost our way that this family has said this to us? Why is it that these two qualities, empathy and dignity, have been in apparent short supply for this family? We are sure that each of us would want to be treated with empathy and dignity were we to find ourselves in need of care or support. Indeed, these are two of the core components of 'compassion' as described in the NHS England 6Cs set of values for all health and social care staff[94].

We have been heartened to see the provision of compassionate and high-quality care for some people with learning disabilities. As we mentioned at the start of this chapter, we need to ensure that these aspects of care are more firmly embedded in systems and processes: the provision of effective multi-disciplinary working that has the person and their family at its centre, is well-coordinated by a named person, and takes a proactive approach to meeting the health and care needs of the individual.

But we cannot ignore the fact that two out of every five reviews (44%) completed in 2019 indicated that the person's care was not of a standard that meets good practice. We can and must do better than that.

Over the years we have made many recommendations about improving the care of people with learning disabilities. Some have been adopted more enthusiastically than others; often by local areas or committed individuals. Many of these will be included in the Action from Learning report accompanying this.

In our view, however, the response to these recommendations has been insufficient and we have not seen the sea change required to reassure the father mentioned above that early deaths are being prevented.

It is long over-due that we should now have concerted national-level policy change in response to the issues raised in this report and previous others. A commitment to take forward the recommendations in a meaningful and determined way is urgently required.

[94] https://www.england.nhs.uk/6cs/wp-content/uploads/sites/25/2015/03/introducing-the-6cs.pdf

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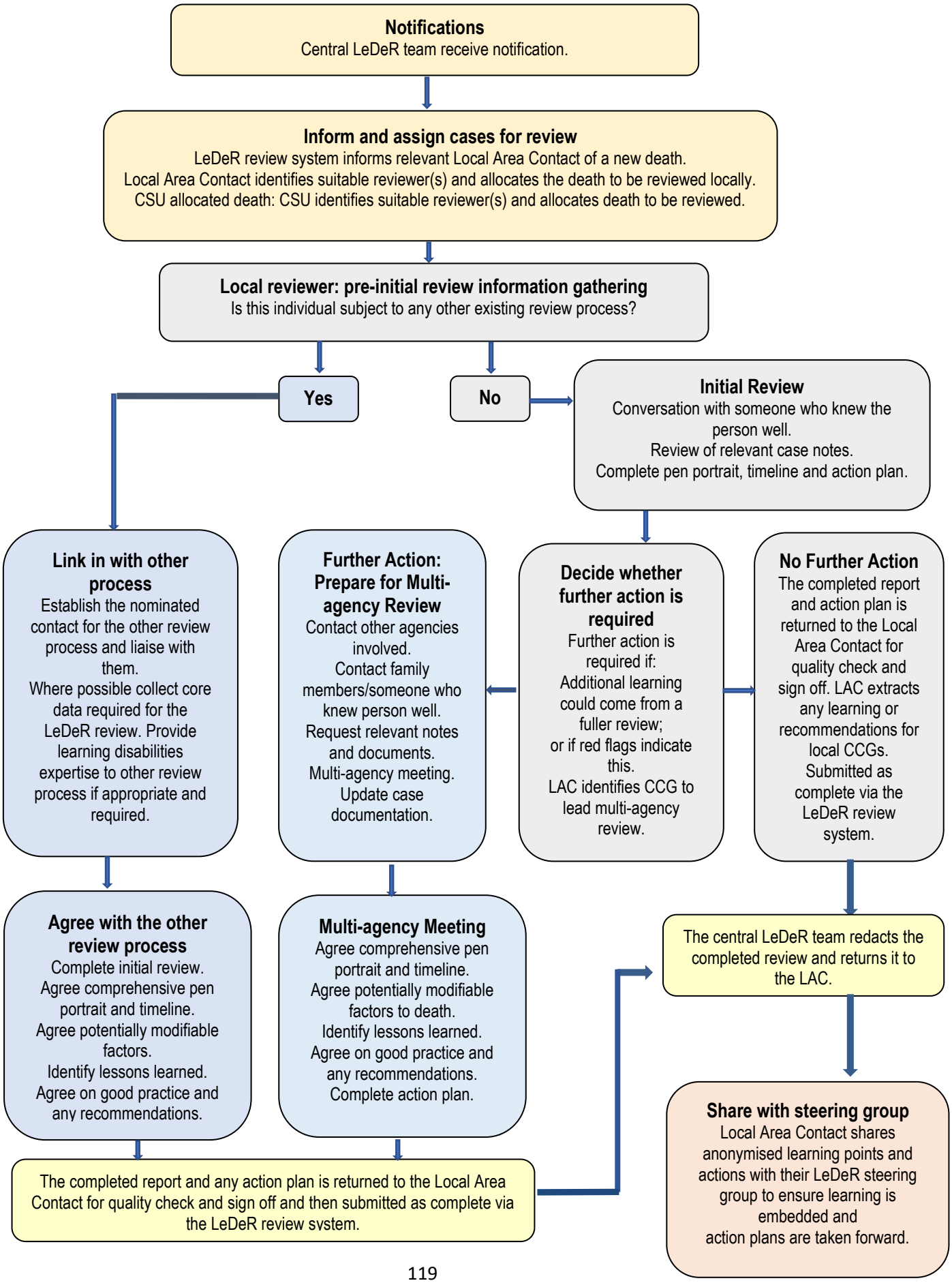
Appendices

Appendix 1: Timeline of the development of the LeDeR programme

2015	1st June – establishment of LeDeR programme in response to significant ongoing concerns about the likelihood of premature deaths of people with learning disabilities. The LeDeR acronym stands for Learning Disabilities Death Review and LeDeR is pronounced as 'leader'. Team based at the University of Bristol responsible for developing and rolling out a review process for deaths of people with learning disabilities that takes a holistic perspective of their health and social care needs and how these needs were met.
2016	Pilot sites established and trial review process. NHS England National Operational Steering Group established. Each NHS region appointed an NHS England Regional Coordinator to guide the roll out of the LeDeR programme across their geographical region. First annual report published October 2016, describing the 'set up' activities for the programme.
2017	April – introduction of the national Learning from Deaths framework in England which states that deaths of people with learning disabilities should be reviewed using LeDeR methodology. LeDeR Steering Groups established to cover all Clinical Commissioning Groups (CCGs) (apart from Bristol, North Somerset and South Gloucestershire which was restructuring at the time).
2018	Second annual report published May 2018. Handover of quality assurance of completed reviews from University of Bristol to NHS England. Train the trainer model, and e-learning introduced for training reviewers and local area contacts. Handover of this from University of Bristol to NHS England. Links and interface between LeDeR and other mortality review programmes and initiatives (e.g. reviews of deaths in acute hospitals; child death review process; medical examiners) to avoid duplication.
2019	Third annual report published May 2018. Publication of Action from Learning report by NHS England. NHS Long Term Plan supports the continuation of the LeDeR programme. LeDeR (NECS) project started to ensure more timely completion of reviews.
2020	Department of Health and Social Care publish response to third LeDeR annual report.

Appendix 2: The LeDeR review process



Appendix 3: Notification of deaths and progress of reviews to 31st December 2019, notification period, by region[95]

ENGLAND	Total	Not yet started	Not yet started %	In progress	In progress %	Completed	Completed %
Total	7145	2027	28%	1923	27%	3195	45%
Jul - Sep 2016	18	1	6%	3	17%	14	78%
Oct - Dec 2016	82	4	5%	3	4%	75	91%
Jan - Mar 2017	170	11	6%	10	6%	149	88%
Apr - Jun 2017	237	13	5%	28	12%	196	83%
Jul - Sep 2017	301	20	7%	31	10%	250	83%
Oct - Dec 2017	557	77	14%	62	11%	418	75%
Jan - Mar 2018	741	136	18%	106	14%	499	67%
Apr - Jun 2018	674	173	26%	100	15%	401	59%
Jul - Sep 2018	581	204	35%	91	16%	286	49%
Oct - Dec 2018	724	254	35%	183	25%	287	40%
Jan - Mar 2019	788	142	18%	325	41%	321	41%
Apr - Jun 2019	733	175	24%	376	51%	182	25%
Jul - Sep 2019	741	302	41%	339	46%	100	13%
Oct - Dec 2019	798	515	65%	266	33%	17	2%

North West	Total	Not yet started	Not yet started %	In progress	In progress %	Completed	Completed %
Total	1062	363	34%	292	27%	407	38%
Oct - Dec 2016	10	1	10%	0	0%	9	90%
Jan - Mar 2017	27	3	11%	3	11%	21	78%
Apr - Jun 2017	61	9	15%	9	15%	43	70%
Jul - Sep 2017	66	13	20%	9	14%	44	67%
Oct - Dec 2017	82	11	13%	17	21%	54	66%
Jan - Mar 2018	85	25	29%	8	9%	52	61%
Apr - Jun 2018	95	41	43%	16	17%	38	40%
Jul - Sep 2018	81	45	56%	9	11%	27	33%
Oct - Dec 2018	119	49	41%	29	24%	41	34%
Jan - Mar 2019	110	20	18%	46	42%	44	40%
Apr - Jun 2019	99	23	23%	53	54%	23	23%
Jul - Sep 2019	100	49	49%	43	43%	8	8%
Oct - Dec 2019	127	74	58%	50	39%	3	2%

[95] NHS England expects most reviews to be completed within six months of the death being notified. Deaths notified after the 30th June 2019 would not therefore be expected to be reviewed by 31st December 2019.

North East & Yorkshire	Total	Not yet started	Not yet started %	In progress	In progress %	Completed	Completed %
Total	1302	336	26%	336	26%	630	48%
Jul - Sep 2016	10	0	0%	0	0%	10	100%
Oct - Dec 2016	36	1	3%	1	3%	34	94%
Jan - Mar 2017	98	7	7%	6	6%	85	87%
Apr - Jun 2017	66	2	3%	6	9%	58	88%
Jul - Sep 2017	65	4	6%	6	9%	55	85%
Oct - Dec 2017	98	13	13%	7	7%	78	80%
Jan - Mar 2018	93	22	24%	14	15%	57	61%
Apr - Jun 2018	110	29	26%	15	14%	66	60%
Jul - Sep 2018	90	27	30%	13	14%	50	56%
Oct - Dec 2018	99	21	21%	30	30%	48	48%
Jan - Mar 2019	157	24	15%	70	45%	63	40%
Apr - Jun 2019	99	20	20%	64	65%	15	15%
Jul - Sep 2019	142	66	46%	67	47%	9	6%
Oct - Dec 2019	139	100	72%	37	27%	2	1%

Midlands	Total	Not yet started	Not yet started %	In progress	In progress %	Completed	Completed %
Total	1284	216	17%	328	26%	740	58%
Jul - Sep 2016	1	0	0%	0	0%	1	100%
Jan - Mar 2017	2	0	0%	0	0%	2	100%
Apr - Jun 2017	11	0	0%	0	0%	11	100%
Jul - Sep 2017	28	1	4%	0	0%	27	96%
Oct - Dec 2017	87	4	5%	4	5%	79	91%
Jan - Mar 2018	138	5	4%	14	10%	119	86%
Apr - Jun 2018	139	8	6%	16	12%	115	83%
Jul - Sep 2018	115	23	20%	22	19%	70	61%
Oct - Dec 2018	142	28	20%	33	23%	81	57%
Jan - Mar 2019	130	16	12%	32	25%	82	63%
Apr - Jun 2019	174	23	13%	58	33%	93	53%
Jul - Sep 2019	154	21	14%	80	52%	53	34%
Oct - Dec 2019	163	87	53%	69	42%	7	4%

East of England	Total	Not yet started	Not yet started %	In progress	In progress %	Completed	Completed %
Total	820	371	45%	192	23%	257	31%
Apr - Jun 2017	27	1	4%	7	26%	19	70%
Jul - Sep 2017	33	0	0%	8	24%	25	76%
Oct - Dec 2017	77	10	13%	11	14%	56	73%
Jan - Mar 2018	95	33	35%	15	16%	47	49%
Apr - Jun 2018	79	40	51%	12	15%	27	34%
Jul - Sep 2018	84	53	63%	9	11%	22	26%
Oct - Dec 2018	80	60	75%	9	11%	11	14%
Jan - Mar 2019	106	26	25%	44	42%	36	34%
Apr - Jun 2019	94	34	36%	48	51%	12	13%
Jul - Sep 2019	64	38	59%	24	38%	2	3%
Oct - Dec 2019	81	76	94%	5	6%	0	0%

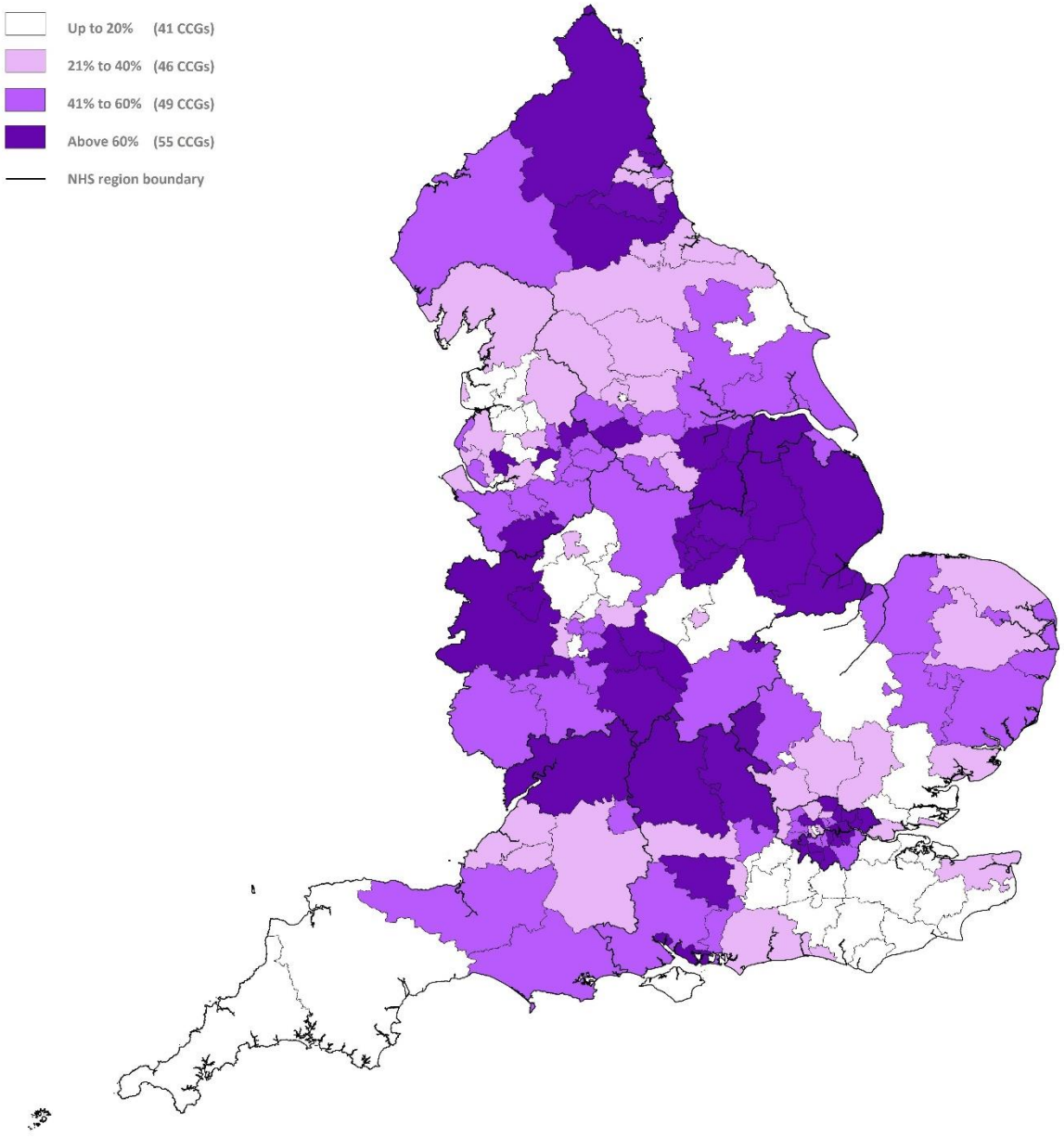
London	Total	Not yet started	Not yet started %	In progress	In progress %	Completed	Completed %
Total	834	111	13%	217	26%	506	61%
Oct - Dec 2016	4	0	0%	1	25%	3	75%
Jan - Mar 2017	18	0	0%	1	6%	17	94%
Apr - Jun 2017	39	1	3%	2	5%	36	92%
Jul - Sep 2017	53	0	0%	3	6%	50	94%
Oct - Dec 2017	70	1	1%	4	6%	65	93%
Jan - Mar 2018	101	1	1%	13	13%	87	86%
Apr - Jun 2018	71	4	6%	8	11%	59	83%
Jul - Sep 2018	63	3	5%	11	17%	49	78%
Oct - Dec 2018	77	7	9%	21	27%	49	64%
Jan - Mar 2019	97	10	10%	36	37%	51	53%
Apr - Jun 2019	65	12	18%	36	55%	17	26%
Jul - Sep 2019	84	26	31%	39	46%	19	23%
Oct - Dec 2019	92	46	50%	42	46%	4	4%

South East	Total	Not yet started	Not yet started %	In progress	In progress %	Completed	Completed %
Total	1155	483	42%	296	26%	376	33%
Jul - Sep 2016	5	1	20%	2	40%	2	40%
Oct - Dec 2016	20	2	10%	1	5%	17	85%
Jan - Mar 2017	9	1	11%	0	0%	8	89%
Apr - Jun 2017	15	0	0%	3	20%	12	80%
Jul - Sep 2017	23	0	0%	1	4%	22	96%
Oct - Dec 2017	85	30	35%	15	18%	40	47%
Jan - Mar 2018	161	46	29%	25	16%	90	56%
Apr - Jun 2018	115	39	34%	18	16%	58	50%
Jul - Sep 2018	98	46	47%	13	13%	39	40%
Oct - Dec 2018	147	84	57%	34	23%	29	20%
Jan - Mar 2019	121	46	38%	45	37%	30	25%
Apr - Jun 2019	107	44	41%	44	41%	19	18%
Jul - Sep 2019	129	68	53%	52	40%	9	7%
Oct - Dec 2019	120	76	63%	43	36%	1	1%

South West	Total	Not yet started	Not yet started %	In progress	In progress %	Completed	Completed %
Total	688	147	21%	262	38%	279	41%
Jul - Sep 2016	2	0	0%	1	50%	1	50%
Oct - Dec 2016	12	0	0%	0	0%	12	100%
Jan - Mar 2017	16	0	0%	0	0%	16	100%
Apr - Jun 2017	18	0	0%	1	6%	17	94%
Jul - Sep 2017	33	2	6%	4	12%	27	82%
Oct - Dec 2017	58	8	14%	4	7%	46	79%
Jan - Mar 2018	68	4	6%	17	25%	47	69%
Apr - Jun 2018	65	12	18%	15	23%	38	58%
Jul - Sep 2018	50	7	14%	14	28%	29	58%
Oct - Dec 2018	60	5	8%	27	45%	28	47%
Jan - Mar 2019	67	0	0%	52	78%	15	22%
Apr - Jun 2019	95	19	20%	73	77%	3	3%
Jul - Sep 2019	68	34	50%	34	50%	0	0%
Oct - Dec 2019	76	56	74%	20	26%	0	0%

Appendix 4: Geographical distribution of completed reviews

Map 1 - LeDeR: The proportion of completed reviews, by Clinical Commissioning Group, to 31st December 2019 (all notifications)



Appendix 5: Leading causes of death by geographical region and Clinical Commissioning Group

Leading causes of death by geographical region and Clinical Commissioning Group. All notifications received in 2018 and 2019 for which ICD-10 codes are available											
	Deaths for which ICD-10 codes available	Bacterial pneumonia		Aspiration pneumonia		Dementia		Sepsis		Epilepsy	
NHS region and CCG	No.	No.	%	No.	%	No.	%	No.	%	No.	%
EAST OF ENGLAND	**564**	**131**	**23%**	**89**	**16%**	**49**	**9%**	**44**	**8%**	**31**	**5%**
NHS Cambridgeshire and Peterborough CCG	71	15	21%	15	21%	*	*	*	*	*	*
NHS Herts Valleys CCG	51	15	29%	*	*	*	*	*	*	0	-
NHS Mid Essex CCG	35	12	34%	*	*	*	*	*	*	*	*
NHS North East Essex CCG	59	19	32%	*	*	*	*	*	*	*	*
NHS South Norfolk CCG	33	13	39%	*	*	*	*	*	*	*	*
LONDON	**530**	**122**	**23%**	**76**	**14%**	**40**	**8%**	**35**	**7%**	**37**	**7%**
NHS Barnet CCG	34	10	29%	*	*	*	*	*	*	0	-
NHS Croydon CCG	41	10	24%	12	29%	*	*	*	*	*	*
MIDLANDS	**946**	**211**	**22%**	**147**	**16%**	**94**	**10%**	**66**	**7%**	**64**	**7%**
NHS Birmingham and Solihull CCG	88	21	24%	14	16%	10	11%	*	*	*	*
NHS Coventry and Rugby CCG	43	10	23%	*	*	*	*	*	*	*	*
NHS Derby and Derbyshire CCG	97	14	14%	13	13%	*	*	*	*	*	*
NHS Lincolnshire West CCG	30	12	40%	*	*	*	*	*	*	*	*
NHS Sandwell and West Birmingham CCG	55	11	20%	14	25%	*	*	*	*	*	*
NORTH EAST AND YORKSHIRE	**741**	**171**	**23%**	**119**	**16%**	**65**	**9%**	**54**	**7%**	**37**	**5%**
NHS Bradford Districts CCG	40	12	30%	*	*	*	*	*	*	*	*
NHS Leeds CCG	47	15	32%	*	*	*	*	*	*	*	*
NHS Newcastle Gateshead CCG	45	15	33%	*	*	*	*	*	*	*	*
NHS Rotherham CCG	25	11	44%	*	*	*	*	*	*	*	*
NHS Sheffield CCG	53	*	*	12	23%	*	*	*	*	*	*
NORTH WEST	**631**	**146**	**23%**	**106**	**17%**	**52**	**8%**	**60**	**10%**	**39**	**6%**
NHS East Lancashire CCG	36	11	31%	*	*	*	*	*	*	*	*
NHS Liverpool CCG	57	11	19%	14	25%	*	*	*	*	*	*
NHS Salford CCG	32	10	31%	*	*	*	*	*	*	*	*

NHS Stockport CCG	39	10	26%	*	*	*	*	*	*	*	*
SOUTH EAST	**831**	**218**	**26%**	**131**	**16%**	**79**	**10%**	**50**	**6%**	**43**	**5%**
NHS Berkshire West CCG	46	15	33%	*	*	*	*	10	22%	*	*
NHS Buckinghamshire CCG	38	10	26%	12	32%	*	*	*	*	*	*
NHS Canterbury and Coastal CCG	36	10	28%	*	*	*	*	*	*	*	*
NHS Coastal West Sussex CCG	43	13	30%	*	*	*	*	*	*	*	*
NHS East Surrey CCG	41	14	34%	*	*	*	*	*	*	*	*
NHS Horsham and Mid Sussex CCG	22	10	45%	*	*	0	-	*	*	0	-
NHS Oxfordshire CCG	85	22	26%	11	13%	*	*	*	*	*	*
NHS South Kent Coast CCG	42	10	24%	*	*	*	*	*	*	*	*
SOUTH WEST	**460**	**136**	**30%**	**55**	**12%**	**54**	**12%**	**35**	**8%**	**24**	**5%**
NHS Bristol, North Somerset and South Gloucestershire CCG	83	20	24%	18	22%	10	12%	*	*	*	*
NHS Gloucestershire CCG	77	24	31%	*	*	*	*	10	13%	*	*
NHS Kernow CCG	51	18	35%	*	*	*	*	*	*	*	*
NHS Somerset CCG	47	12	26%	*	*	*	*	*	*	*	*
NHS Wiltshire CCG	38	13	34%	*	*	*	*	*	*	*	*

Notes:

The name of any CCG with fewer than 10 deaths for all of the listed leading causes of death has been removed.

*number less than ten.

Appendix 6: Examples from the range of recommendations made by the reviewers and multi-agency review panels

The following comments are drawn from completed reviews, illustrating the range of recommendations made and, in some cases, actions taken as a result of the death. We have presented these thematically.

Care coordination, communication and sharing information

- An assigned worker should take the lead in coordinating professional involvement.
- Provide a lead consultant for people with learning disabilities in acute settings.
- Better coordination and utilisation of emergency Health Action Plans and increased understanding of who is responsible.
- Provide an active learning disabilities nurse in the community.
- Clinical teams should use joint paperwork and record keeping systems to promote shared understanding.
- There will be a review by the CCG of the pathway around specialist care and epilepsy using NICE Guidance; this will include a review of communication and handovers from specialist services such as neurology to GPs.
- Appropriate communication system is needed in order to evidence that all changes in care are communicated to the staff team in a timely manner.
- Better liaison needed between tertiary hospitals and community teams so that discharge can be better coordinated.
- Record keeping must improve as there are discrepancies within the medical notes.
- Communicate with all agencies involved in a person's care, especially around decision making.
- Improve sharing of intelligence between CQC and staff to include local authority staff as well as clinical staff so the list of approved nursing homes is adequately monitored and reported.
- Ensure that information is shared in relation to support needs on hospital admission and discharge.
- There should be a hospital admission plan like a discharge plan.
- There should be a standardised handover when a patient is moved between wards.
- Clearer communication is needed between out -of-hours GP and regular GP.
- Attach a nurse to the patients care in-between appointments who could follow up on tasks.
- Staff teams to receive timely copies of discharge summaries.
- Protocols to reflect importance of communication and liaison with a named GP regarding safeguarding risks to people with learning disabilities.
- Care homes should adopt a policy of asking for copies of discharge letters if they have not received one, including after a death.
- Earlier signposting by the hospital to the community learning disabilities team (CLDT) for support; and more

awareness of the services provided within the CLDT and how they can support someone with a learning disability.

- Provide parents with information about how they can make contact with the CLDT should they require support.
- For complex patients with health risks who are not engaging with services, a multi-disciplinary approach to managing their health and social care needs may be appropriate. This could be through the mechanism of regular scheduled meetings attended by their GP, the community nurses and other external agencies involved in their care and support.
- The Speech and Language Therapist service had reflected on how they could assure guidelines and recommendations they make in relation to feeding regimes are adhered to. They now ask provision managers how the information they provide will be disseminated to the whole team. They prepare a single page guidance for staff regarding specific feeding requirements of the people they support with learning disabilities. Home managers subsequently complete observations of staff in their food preparation for service users to ensure guidelines are being followed.
- Services should ensure there are multi-agency pathways to potential community services available to people with learning disabilities depending on their individual need.
- Health and social care professionals should work together to facilitate discharge from hospital at the earliest opportunity.
- Need to develop a standardised approach to discharge planning, which ensures care coordination and key worker identification.
  Communications and plans need to be detailed and shared across services, prior to discharge. Potential fast track mechanism for Continuing Healthcare assessment to promote early discharge is being reviewed.

System-level actions or recommendations

- Patient records should be held on one shared system.
- Hospitals and care homes need to follow up when people with learning disabilities do not attend health appointments.
- Missed appointments for vulnerable patients should be followed up and must not result in automatic discharge.
- Funding for supporting people with learning disabilities in hospital needs to be addressed.
- Increase the capacity for renal dialysis – more beds, more filters and more staff.
- Provide a facility outside of intensive care unit to dialyse complex patients as necessary.
- Acute liaison team to develop flagging system so that people with learning disabilities are automatically referred to them on admission.
- Decommissioned services transfer full experience/records to new learning disability providers – particularly important when the residents moving do not have capacity to manage their own support needs.

- Development of a more comprehensive hospital passport is needed.
- There should be more effective and consistent weekend cover for patients with swallowing issues that minimise or eliminate treatment delays where the patient could be at risk of aspiration.
- Shorter waits for delivery of appropriate wheelchair; better communication between wheelchair services and community services/carers.
- Improve speech and language therapy response times for swallowing assessments.
- All nursing homes to have an nhs.net account that can be accessed by various staff within that setting to enable secure, timely communication and sharing of information.
- There should be a mechanism for admitting vulnerable patients direct to hospital rather than via A&E.
- Investigate whether information technology system can flag where more than one vulnerable person lives at the same address.
- Review whether existing specialist epilepsy services are sufficient to meet local demographic need.
- Staff teams must be empowered to report if they see unfair practice.
- Improve county-wide access to wheelchair scales.
- Review Speech and Language Therapy provision for people with learning disabilities.
- It is recommended that there is an increase of speech and language therapists and physiotherapists to support people with learning disabilities in the community.
- Improve access and opportunities for physiotherapy input for people with learning disabilities.
- Review information sharing and cross-boundary approach to the provision of specialist learning disability services.
- Improve the transition process from child to adult services.
- Implement a protocol for the management of deteriorating residents within the care home.
- A standard protocol should be established which sets out the level of observation which should be implemented and maintained for those with signs of deteriorating physical health.
- Review of communication/IT systems in primary care/GP practice to ensure appropriate adjustments are made when consulting or communicating with people with learning disabilities. This will include how significant issues are flagged on the system.
- Diagnosis of a cancer should generate a referral to the community learning disabilities team for support.
- It is recommended that the dementia pathway in the community for people with learning disabilities is resourced with cognitive stimulation therapy materials.
- RESPECT documentation to be implemented across all health care organisations.
- Flagging system to identify people with learning disabilities when they access the hospital to be put in place.
- Development of a hospital discharge policy to include discharge planning meeting/discussions as standard

practice for all discharges of people with learning disabilities, including family and carers.

The provision of training

- Residential homes to be made aware of the availability of Continuing Healthcare fast-track funding to enable patients to return home to die.
- Training for staff about supporting people with learning disabilities.
- Learning disabilities training to be included on nurse training curriculum nationally as a module.
- Offer GPs training in learning disability awareness.
- Offer learning disability awareness training to A&E staff.
- Mandatory training on learning disabilities, reasonable adjustments and relevant legislation to improve skills and understanding across all health services.
- Train GPs in relation to Down's syndrome.
- Learning disability awareness training for consultants.
- Training for staff in care homes on managing health conditions of people with learning disabilities.
- Support family carers of people with learning disabilities by providing training to help them to manage specific conditions.
- Provide additional triage training for GPs.
- Clinical training for employees in nursing homes so that they can provide the required level of care and support.
- All registered nurses working in clinical areas should be trained to utilise the Modified Early Warning system.
- Training for all health and social care providers in regard to understanding the changing needs of vulnerable people and how to record and respond to health and social needs in a timely way.
- There needs to be better recognition that people with learning disabilities may have difficulty in communicating pain.
- All providers should be made aware of the potential for choking on inedible objects and ensure their policies (such as Accident and Incident policies and Safer Swallowing policies) cover this as well as edible objects.
- Training for all health and care providers on the importance of maintaining hydration to help protect someone's kidneys and that they should record fluid intake especially when someone is unwell.
- Guidance is required on the development of an electronic home care package tool for adults requiring ongoing support.
- All agencies to be aware of the self-neglect strategy and protocol around this.
- Staff must understand and implement correct postural management.
- The national guidance on the dysphagia pathway should be shared with care providers by community speech and language therapists.
- It is recommended that dysphagia awareness training is offered to supported living providers emphasising how a person should be fed, and which equipment should be used.
- It would be helpful if the neurology department could advise patients on

the use of technology for monitoring epilepsy.
- Wider awareness of the use of Disability Distress Assessment Tool (DISDAT) within care providers, primary and secondary health services.
- Ward staff should be reminded of the importance of the hospital passport and make full use of them.
- Primary care should have guidance on how to seek support if they have difficulty carrying out annual health checks due to the person refusing aspects which are essential to support their health.
- Training on sepsis awareness, diagnosis and management for residential home staff and medical professionals.
- Competency-based training in regard to the Mental Capacity Act and Deprivation of Liberty legislation. Refresher training for this should be mandatory.
- Further training in Mental Capacity Act legislation including Best Interests decision making processes.
- Review Deprivation of Liberty Safeguards training / provide briefing to support timely Best Interests decision making.
- Review the training needs for staff around Mental Capacity Act and Best Interest Decision.

Adherence to legislation – the Mental Capacity Act and Equality Act

- The records of all individuals with learning disabilities to be appropriately flagged to ensure reasonable adjustments are offered.
- Roll out awareness by distribution of posters in patient areas highlighting the need for reasonable adjustments and how patients and their carers can request this.
- More information on alert screen regarding reasonable adjustments.
- GP practices need to be proactive and consider if their patients with a learning disability who come unaccompanied to appointments need support to understand their health and options.
- All agencies should review their practices concerning reasonable adjustments (timely appointments/understanding individual needs for implementing shorter waiting times - prioritising/calm waiting areas; clear personal health record with chronological information - e.g. recording seizures/falls).
- Greater clarification of the application of the Mental Capacity Act is required.
- If someone is unable to attend a Best Interest meeting, they should send a representative; it is not acceptable to request a second Best Interest meeting if a unanimous decision has been made and all present are in agreement. The decision made in the person's best interest should be abided by without further delay.
- Improved education around decision making for treatment and clarity over who is the decision maker for Best Interests decisions.
- Better documentation of whether mental capacity assessments have taken place and how Best Interests decisions are made.

- Uncertainty about mental capacity assessments and use of DOLS in the acute setting – guidance needs to be explicit on this.
- It should be highlighted to GPs to make referrals to the community learning disability teams where there is a health need that may require a mental capacity assessment and a Best Interest decision.
- Every service user assessed as not having capacity to manage their own physical health needs should have a clear treatment and care plan which gives explicit instruction to all team members required to care for that individual. This should incorporate the following: (i) A multi-disciplinary team member identified as responsible for decision making in relation to the plan. (ii) A date for review of the plan. (iii) Instruction for all staff on how deviation from the care plan should be managed. (iv) Instruction on the use of restrictive practices which support staff teams to make decisions when non-compliance is evident.
- Explaining to families during transition and beyond about legislation, including their rights as the person's family and that they are unable to consent and refuse care on behalf of another adult, unless they have sought permission through the courts as an attorney.
- The wider promotion and use of non-statutory advocates to represent the individual's best interests at times when decisions regarding care and treatment need to be made, particularly where there are differences of opinion between family and health professionals.
- Acute trust should consider documenting Best Interests' discussions better, maybe even using MCA forms.
- Clearer processes around clinical decisions within best interest meetings.
- Improved knowledge and awareness of the role of Independent Mental Capacity Advocate in secondary care services.
- Practitioners need to demonstrate the application of the Mental Capacity Act principles in practice.
- Mental Capacity Act record-keeping has become a priority across services, to promote clearer documentation.
- The GP practice should review Mental Capacity Act, its application to practice, and training compliance

Professional practice and the provision of care

- The person's parents would like all learning disability annual health checks to be mandatory as this will formalise treatment/action/care plans specific to the individual.
- Improve completion of health action plans following an annual health check.
- Promote the use of escalation to access safeguarding advice and provision.
- Anyone with a learning disability who has complex unmet needs should receive a multi-agency review to ascertain a care plan to support them, detailing responsibilities of each agency involved and provide clear guidelines for carers.
- Doctors to ensure that they complete a full assessment of vital signs when a

patient is displaying symptoms that may require further investigation.
- Seizure diaries to be maintained and shared with GP at epilepsy reviews.
- Attention to recording fluid intake to ensure that the person does not become dehydrated, especially where vomiting or diarrhoea are present and communication with the person is difficult for whatever reason.
- Must implement the use of the MEWS (modified early warning score) to ensure the identification of clinical deterioration.
- Use the New Early Warning Score digital kit to recognise sign of deterioration in physical health.
- A holistic approach is needed when supporting people with learning disabilities.
- Professional curiosity should be maintained, rather than looking solely at the issues in hand to identify issues.
- A review of physical health care plans should be undertaken to ensure they are fully integrated into each person's Integrated Treatment and Care Plan.
- Community Learning Disability Nursing Team to review the dental and medication section of the 'Head to Toe' health screening to cover dental refusal and actions following this.
- Learning disability liaison nurses will ensure that families of people with learning disabilities are made aware of Patient Advice and Liaison Service at the point of admission.
- Community monitoring of Stage 3 chronic kidney disease and care programmes for staff/service users.
- Acute liaison nurses to raise their profile within the hospital.
- GP practices to make available at least two GPs in the practice who would be the leads to support people with a learning disability.
- If patients are seen on a home visit list, GPs should set aside time to follow up on any wider concerns/recommendations.
- Patients must be present at their annual health check. If a patient is not present, then their annual health check should be rescheduled.
- Review policy about people refusing medications, and how staff respond and record their actions.
- Providers and commissioners should be clear with each other not just about the number of hours of support but how they will be delivered.
- Further publicity about the potential of sudden death in epilepsy and associated alerts is needed.
- Care homes and health care providers need to engage with family members to keep them involved and informed.
- There needs to be assessment of support provided to carers and an increase in this support where necessary.
- Family concerns to be listened to.

Appendix 7: Summary of some recommendations made in previous reports about deaths of people with learning disabilities, and government responses to these

Poor care coordination and communication between agencies

Recommendations made	Response to recommendations
Learning Disabilities Mortality Review (LeDeR) programme. Third Annual Report 2018. https://www.hqip.org.uk/resource/the-learning-disabilities-mortality-review-annual-report-2018/#.XmfBt0B2vg9 ***Recommendation 7.*** Guidance continues to be needed on care-coordination and information sharing in relation to people with learning disabilities, at individual and strategic levels. **Learning Disabilities Mortality Review (LeDeR) programme. Second Annual Report 2017.** http://www.bristol.ac.uk/university/media/press/2018/leder-annual-report-final.pdf ***Recommendation 4.*** 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. **CIPOLD (2013)** http://www.bris.ac.uk/media-library/sites/cipold/migrat	**Department of Health and Social Care (2020) The Government response to the third annual Learning Disabilities Mortality Review (LeDeR) Programme report.** https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/865288/government-response-to-leder-third-annual-report.pdf 2.35 In the Government's response to the 2018 LeDeR report, we committed to 'Undertake a rapid review of best practice in care co-ordination/key working for people with a learning disability, focused on health and wellbeing, to inform guidance for the NHS on care-co-ordination.' 2.36 We are working with the Institute of Public Care at Oxford Brookes University to gather existing evidence and case studies of care co-ordination for people with learning disabilities. The IPC held focus groups with people with learning disabilities and their families and carers. Evidence from a number of different approaches to care co-ordination have been identified. Examples from across the country have also been drawn together to demonstrate best practice. 2.37 Care co-ordination is a complex area, particularly in the specific context of improving health and wellbeing of people with learning disabilities. It is therefore important that we properly understand the challenges and issues faced prior to establishing next steps. DHSC will publish an evidence review of care co-ordination for people with learning disability, focused on health and wellbeing. Once this work is complete, we will be better placed to understand how this can be used to inform how care co-ordination is delivered across the health and social care sector for people with a learning disability, particularly in regards to developing guidance. Action: DHSC to publish an evidence review of care co-ordination for people with learning disability, focused on health and wellbeing. By summer 2020. **The Government response to the Learning Disabilities Mortality Review (LeDeR) Programme Second Annual Report (2018)** https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/739560/government-response-

ed/documents/fullfinalreport.pdf ***Recommendation 4.*** A named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions. **Michael, J. (2008) Healthcare for All** https://webarchive.nationalarchives.gov.uk/20130105064250/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255 ***Recommendation 3.*** Family and other carers should be involved as a matter of course as partners in the provision of treatment and care, unless good reason is given, and Trust Boards should ensure that reasonable adjustments are made to enable them to do this effectively. This will include the provision of information but may also involve practical support and service co-ordination.	to-leder-programme-2nd-annual-report.pdf We agree that coordinating care across and within health and care services is a crucial determinant of outcomes. We will be reviewing best practice on care coordination to identify approaches that work best for people with a learning disability with two or more long-term conditions. Action 2: NHS England to report annually to the DHSC on progress made on the learning into action workstream regarding improvements in interagency communication achieved through local action. By March 2019. Action 8. Undertake a rapid review of best practice in care-coordination / key working for people with a learning disability, focused on health and wellbeing, to inform guidance for the NHS on care-co-ordination. DHSC. March 2019. **Department of Health (2014) Premature Deaths of People with Learning Disabilities: Progress Update** https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/356229/PUBLISH_42715_2902809_Progress_Report_Accessible_v04.pdf 3.2. An overarching national initiative to address the fragmentation of care is the Better Care Fund. This provides an opportunity for local services to improve the lives of some of the most vulnerable people in our society. It ensures closer integration between health and social care services to work more closely together in local areas, based on a plan agreed between the NHS and local authorities. Local plans were submitted in April. 3.4. Published on April 14th, Transforming Primary Care sets out the Department and NHS England's joint vision for safe, proactive, personalised care for those who need it most. From September 2014, over 800,000 people with the most complex needs will experience a step change in their care, with GPs developing a proactive and personalised programme of care and support tailored to their needs and views – the Proactive Care Programme. 3.5. The Programme will be provided for at least two per cent of adults on GPs' practice list with the most complex needs. The decision about who is identified to receive the Programme is ultimately up to general practitioners' discretion. However, we anticipate that the cohort of people will contain a number of people with learning disabilities. **Government response to the recommendations in the Confidential Inquiry into premature deaths of people with learning disabilities (2013).**

	https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/212077/Government_Response_to_the_Confidential_Inquiry_into_Premature_Deaths_of_People_with_Learning_Disabilities_-_full_report.pdf The DH agrees with this recommendation and this is also a core aim of NHS England. In particular, domain 2, 'Improving the quality of life for people with long term conditions', is aiming to have a known contact for individuals who have multiple long-term conditions who can: • Coordinate a person's care. • Communicate with other health professionals. • Be involved in care planning with the individual for future needs. 23. NHS England will make care coordination a central part of its strategy to help people with more complex healthcare needs benefit from personalised care and know who to turn to for advice in the event of deterioration in their condition. This will include approaches to identify those people who need disease or case management to manage their condition. 24. NHS England will support named healthcare coordinators, usually located in primary and community care settings, being available to people so they know who to turn to when they need them. In particular, NHS England will: • work with the Association of Directors of Adult Social Services (ADASS) and the Association of Directors of Children's Services (ADCS), to develop practical resources for commissioners of services for people with learning disabilities of all ages, including children and young people; and, • examine the potential for tighter requirements in the NHS Standard Contract for the provision of named healthcare coordinators for people with learning disabilities. This will be done by the new clinical lead for learning disabilities, who will be recruited to work on domain 2 in NHS England by August 2013. NHS England will publish further details later in 2013. **HM Government (2009). Valuing People Now: a new three-year strategy for people with learning disabilities. A response to Michael's Healthcare for All (2008)** https://webarchive.nationalarchives.gov.uk/20130105064234/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093375.pdf Recommendation 3. Response: we accept this recommendation.

Delays in the diagnosis and treatment of illness

Recommendations made	Response to recommendations
Learning Disabilities Mortality Review (LeDeR) programme. Third Annual Report 2018. https://www.hqip.org.uk/resource/the-learning-disabilities-mortality-review-annual-report-2018/#.XmfBt0B2vg9 ***Recommendation 6.*** The Department of Health and Social Care, working with a range of agencies and people with learning disabilities and their families, to prioritise programmes of work to address key themes emerging from the LeDeR programme as potentially avoidable causes of death. The recommended priorities for 2019 include: i) recognising deteriorating health or early signs of illness in people with learning disabilities and ii) minimising the risks of pneumonia and aspiration pneumonia. **CIPOLD (2013)** http://www.bris.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf ***Recommendation 7.*** People with learning disabilities to have access to the same investigations and treatments as anyone else, but acknowledging	**Department of Health and Social Care (2020) The Government response to the third annual Learning Disabilities Mortality Review (LeDeR) Programme report**. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/865288/government-response-to-leder-third-annual-report.pdf 2.29 We agree that key themes identified in LeDeR reports should inform the prioritisation of programmes of work. NHS England have set out the work underway in response to national themes identified in the LeDeR reviews, including relating to the recommended priorities above in their Action from Learning report (2019). 2.30 The LeDeR report highlighted a number of issues related to the quality of care of people with learning disabilities, including delays in identifying that a person was ill, recognising further deterioration, and accessing and receiving appropriate medical care. Failure to recognise or act on signs a patient is deteriorating can result in missed opportunities to provide the necessary care to give the best possible chance of survival. 2.31 The 2019 Action from Learning report was the first report on work to translate learning into action in relation to the LeDeR programme and set out work relating to the specific issues of acute deterioration, including sepsis and aspiration pneumonia. Action: NHS England will publish another Action from Learning report to demonstrate the range of changes that have taken place as a result of the learning from LeDeR reviews. Spring 2020. **Government response to the recommendations in the Confidential Inquiry into premature deaths of people with learning disabilities (2013).** https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/212077/Government_Response_to_the_Confidential_Inquiry_into_Premature_Deaths_of_People_with_Learning_Disabilities_-_full_report.pdf 30. NHS England is committed to reducing inequalities in outcomes for people with learning disabilities. The Mandate set by the Government requires NHS England to deliver improved outcomes for all people. Success will be measured not only by the average level of improvement but also by progress in reducing health inequalities

and accommodating that they may need to be delivered differently to achieve the same outcome.	and unjustified variation in outcomes, including for people with learning disabilities. 31. The factors that contribute to inequalities in outcomes are complex and it is clear that a number of approaches to addressing and improving these are needed. NHS England is currently developing its approach to reducing premature mortality. As part of this it is working with learning disabled people and family carers to understand the factors that impact on their ability to access services in the same way as the rest of the population. NHS England is clear that if it can improve the way that services respond to the needs of the most vulnerable in society, then those improvements are also likely to deliver broader benefits for the general population. 32. NHS England will continue to develop its overall approach to supporting people with learning disabilities and family carers. In the meantime, NHS England will: • Work with Association of Directors of Adult Social Services (ADASS) and Association of Directors of Children's Services (ADCS) to develop practical resources for commissioners of services for people with learning disabilities, including children and young people with the potential for new NHS contract specifications for specialist learning disability services and for models for rewarding best practice through the Commissioning for Quality and Innovation (CQUIN) framework. • Support CCGs in their work with local authorities to ensure that people of all ages in vulnerable circumstances, particularly those with learning disabilities and autism, receive safe, appropriate and high-quality care. This includes supporting effective, integrated education, health and care planning for children and young people with a learning disability who have special educational needs. • Monitor the progress of the NHS in improving outcomes for all people and reducing variation in outcomes, including for those with learning disabilities, in England. • assess scope for publishing comparable practice level data and as part of this work consider what scope there is for capturing data in relation to people with learning disabilities.

Application of the Mental Capacity Act

Recommendations made	Response to recommendations
Learning Disabilities Mortality Review (LeDeR) programme. Second Annual Report. 2017. http://www.bristol.ac.uk/university/media/press/2018/leder-annual-report-final.pdf	**The Government response to the Learning Disabilities Mortality Review (LeDeR) Programme Second Annual Report (2018)** https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/739560/government-response-to-leder-programme-2nd-annual-

Recommendation 8. Local services strengthen their governance in relation to adherence to the MCA, and provide training and audit of compliance 'on the ground' so that professionals fully appreciate the requirements of the Act in relation to their own role. **Select Committee on the Mental Capacity Act 2005. Mental Capacity Act 2005: post-legislative scrutiny (2014).** https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/13902.htm ***Recommendation 1.*** In the first instance we recommend that the Government address as a matter of urgency the issue of low awareness among those affected, their families and carers, professionals and the wider public. (paragraph 109.) ***Recommendation 3.*** We recommend that overall responsibility for implementation of the Mental Capacity Act be given to a single independent body. This does not remove ultimate accountability for its successful implementation from Ministers, but it would locate within a single independent body the responsibility for oversight, coordination and monitoring of implementation activity across sectors, which is currently lacking. (paragraph 114). ***Recommendation 5.*** We recommend that the standards against which the CQC inspects should explicitly incorporate compliance with the Mental Capacity Act, as a core requirement that must be met by all health and care providers. Meeting the requirements of the empowering ethos of the Act, and especially in terms of actively enabling supported decision-making, must be given equal status with the appropriate use of the	report.pdf 50. We acknowledge that more needs to be done to embed the principles of the MCA in everyday practice. Every part of the system has a role to play and the Government is showing leadership on this through the National Mental Capacity Forum. Action 21. The Department of Health and Social Care to update on progress regarding the National Mental Capacity Forum. DHSC. 2019. Action 22. NHS England to distribute additional best practice guidance on the MCA, learning disabilities and urgent care situations. NHS England. November 2018. Action 23. The CQC to further develop inspection expertise to assess the quality of MCA application and practice. CQC. October 2019. **Department of Health (2014) Premature Deaths of People with Learning Disabilities: Progress Update** https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/356229/PUBLISH_42715_2902809_Progress_Report_Accessible_v04.pdf 5.3 … relevant commitments include: • The Social Care Institute for Excellence (SCIE) has been asked to conduct a review of MCA guidance to identify 'gold standard' materials for the health and care sector by the end of 2014. These materials can then be jointly endorsed by national system partners and their existence advertised. They will be easily available online. • Health Education England (HEE) is conducting a review of its training programmes to determine their compliance with the principles of the MCA. • NHS England has agreed to explore best practice in the use of commissioning as a tool for encouraging implementation of the MCA. 5.5. It is important that MCA advice should be available whenever it is needed. Most hospitals and local authorities have a Mental Capacity Lead person, whose job it is to carry out training needs analyses, commission or offer training, and to help with difficult situations. There should be staff trained in the MCA available 24 hours a day, and there should be specialist advice available in all care settings.

deprivation of liberty safeguards, or their replacement provisions (paragraph 127). ***Recommendation 6.*** We recommend the Government work with professional regulators and the medical Royal Colleges to ensure that the Act is given a higher profile. This work should emphasise the empowering ethos of the Act, and the best interests process as set out in section 4 of the Act. In future, we would expect the responsibility for this to sit with the independent oversight body. (paragraph 138). ***Recommendation 36.*** We recommend as a matter of urgency that the Government take steps to establish regular and dedicated monitoring of implementation of the Act, and that this should include all the sectors across which the Act applies. (paragraph 35). **CIPOLD (2013).** http://www.bris.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf ***Recommendation 10.*** Mental Capacity Act advice to be easily available 24 hours a day. ***Recommendation 12.*** Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care. (i) We recommend the development, by the Department of Health, of an approved e-learning package with worked examples and case studies, supported by individual applied training in the practice environment. (ii) Training activities regarding the Mental Capacity Act must be monitored by NHS England and Clinical Commissioning Groups as part	5.6. In addition, the Department is commissioning a review of guidance materials on the MCA. This review will ask stakeholders to submit any tools and guidance for review by an independent panel prior to being made available through an online portal. 5.7. HEE is committed to improving the education and training of the NHS workforce by working with the Department of Health, providers, clinical leaders, Royal Colleges and other partners. HEE has signed the Winterbourne View Concordat, and will also ensure the findings of the Confidential Inquiry are acted upon as it progresses work on educating and training staff that are treating and caring for people with learning disabilities, autism and challenging behaviour. In particular: • To develop e-learning resources for those working with children, young people and adults across the full spectrum of disabilities, including those with a learning disability, special educational needs or complex health needs. This will include opportunities for training in how to support individuals in line with the provisions of the MCA. • In response to the House of Lords report, Health Education England is reviewing its education and training programmes to determine their compliance with the principles of the MCA. Health Education England will also consider the benefit of including MCA compliance as a feature of our standard contract with education providers… **Government response to the recommendations in the Confidential Inquiry into premature deaths of people with learning disabilities (2013).** https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/212077/Government_Response_to_the_Confidential_Inquiry_into_Premature_Deaths_of_People_with_Learning_Disabilities_-_full_report.pdf 47. The DH agrees it is important that MCA advice should be available at all times. 48. Most hospitals and local authorities have a Mental Capacity Lead person, whose job it is to carry out training needs analyses, commission or offer training, and to help with difficult situations. There should be staff trained in the MCA available 24 hours a day, and there should be specialist advice available in all care settings. 49. CCGs are responsible for commissioning this for the NHS, and all CCGs have a named MCA lead as part of

of their contracts with service providers	their authorisation process. However, their arrangements for commissioning advice vary, some commission it through access to private lawyers, some through access to their own lawyers, while others rely on their consultants having the required expertise. 56. The DH is working with partners, including relevant Royal Colleges, HEE and Skills for Care to develop e-learning resources for those working with children, young people and adults across the full spectrum of disabilities, including those with a learning disability, special educational needs or complex health need. This will include opportunities for training in how to support individuals in line with the provisions of the MCA. 57. All CCGs have a named MCA lead. These named leads have responsibility for commissioning MCA compliant services and for monitoring that the services meet the requirements of the MCA. CCGs will be held accountable by NHS England, who will be asked to report to the DH on evidence of compliance.

Appendix 8: Key findings (2018 – 2019) from the repository of anonymised case reports

As part of the LeDeR programme we have developed a national repository (collection) of anonymised case reports pertaining to people with learning disabilities.

The repository holds summaries of reviews including Safeguarding Adult Reviews (formerly Serious Case Reviews), Serious Incident Reports and Ombudsman reports conducted in England. It does not include any reviews carried out as part of the LeDeR programme.

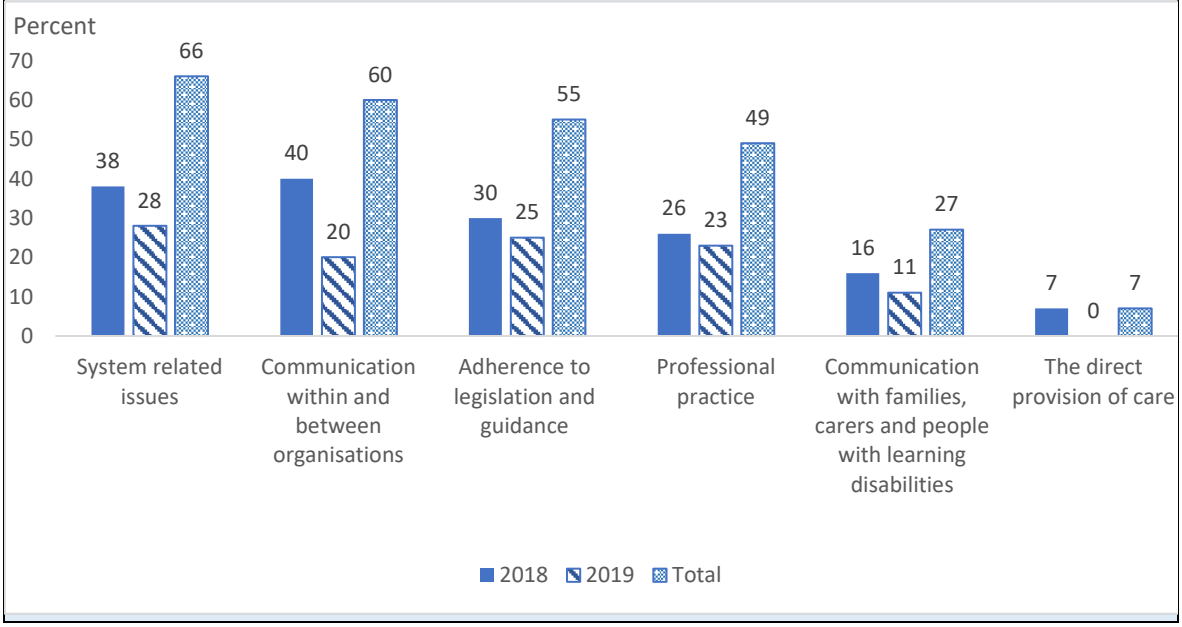
The repository is formed of anonymised examples of 'near misses' (serious incidents), with key learning points and recommendations for each case. These are then thematically analysed to draw out common learning points which can be shared nationally. The repository is available at: http://www.bristol.ac.uk/sps/leder/repository/

Here we highlight the key recommendations from reviews for the period January 2018 to December 2019. The recommendations are 'calls for action' that are broad in scope and apply beyond the specific case under consideration.

The recommendations from the reviews in the repository fall into six different themes:

1. Systems related issues.
2. Communication within and between organisations.
3. Adherence to legislation and guidance.
4. Professional practice.
5. Communication with families, carers and people with learning disabilities.
6. The direct provision of care.

Recommendations (grouped) from reviews included in the repository



System related issues

The most frequent recommendations made (66 recommendations) were in relation to systems issues – the introduction, change, or improvement of processes and practices.
Recommendations suggested:

- Practice guidance regarding transition processes should be further developed. Information and guidance should be made available and accessible for the person transitioning, families, carers, and professionals. This may be in relation to transitioning between service providers, or from children to adult services.
- The extent of family involvement should be understood across agencies involved.
- 'Out of area' care home placements must be reviewed, and the frequency and timeliness of these monitored. Where a person receives 'out of area' care, the placing authority should ensure the provider has a suitably skilled team.
- Hospital discharge policies must ensure best practice in making safe and effective arrangements for people with complex needs.
- Policies and procedures for triaging safeguarding concerns should be reviewed, enhanced, and escalation policies made clear.

"Commissioners must set out their plans for assessing the quality of provision in the local area." (report author).

"Safeguarding adult board should assure itself that …social workers are provided with appropriate training and risk assessment management tools used in responding to safeguarding concerns." (report author).

Communication within and between organisations

The need for improved communication within and across organisations was identified in 60 recommendations. This included planning multi-agency meetings, being able to have difficult conversations with colleagues, and the need for a lead worker/agency for coordinating multi-agency care.

Recommendations suggested:

- Multi-agency working should involve all agencies engaged in the care of a person, including those outside of the health and social care sector.
- Where there are multiple agencies involved, a lead agency should be appointed.
- A culture of collaboration should be encouraged across agencies.
- Support workers familiar to the individual should be valued and utilised across agencies, with additional support for this where required.
- Effective communication is needed between all agencies and the family if a person is admitted to hospital.

"There needs to be a named professional responsible for the effective coordination and review of

the care arrangements." (report author)

"Care providers must ensure that they have communication plans in place which ensure that information sharing with other agencies is easily accessible and person centred." (report author).

Adherence to legislation and guidance

Concern about adherence to current legislation and guidance was identified in 55 recommendations. The legislation most frequently mentioned was the Mental Capacity Act, the Care Act and the Equalities Act.

Recommendations suggested:

- Mental Capacity Act training to be enhanced, including responsibilities about using an Independent Mental Capacity Advocate (IMCA).
- Where compliance to legislation or guidance is found lacking, investigations should be undertaken.

"Staff supporting people with a learning disability should have clear policies, procedures and support in place to escalate concerns where the mental capacity framework is not being followed." (review author).

"A review of practices is needed regarding the provision of advocacy for adults with complex physical health needs and learning disability." (report author).

Professional practice

Recommendations that called for further or enhanced training for staff was identified 49 times. These were mainly in relation to recognising warning signs, record keeping, and cultural issues.

Recommendations suggested:

- Appropriate training on self-neglect must be provided.
- Professionals should be clear about when and how to report a safeguarding concern.
- Ensure professionals are aware of how to report poor practice when witnessed.
- Ensure staff are aware of when to involve an outside agency for assistance.
- Meetings should be clearly documented, and notes reviewed for accuracy and shared.

"Clarify what is adult safeguarding and what is poor practice or a "quality" concern, the routes for concerns to be raised, and the expectations of reporting on all agencies." (report author).

"Safeguarding Adults Board should seek to challenge agencies that operate a "Did Not Attend policy". Agencies should consider renaming and operating the policy as "Was Not Brought". (report author).

Communication with families, carers and people with learning disabilities

There were 27 recommendations that referred to the need for regular or improved communication with people with learning disabilities, their families, and carers.

Recommendations suggested:

- Development of information materials for families when their relative moves to a care/supported living setting.
- Assess 111 procedures in relation to patients who have communication difficulties or additional needs.
- Ensure that families are able to express any concerns.
- There should be support available for people with learning disabilities, their families, and carers to express their views.
- Guidance is required about balancing the views of the family with those of others.

"GPs should consider the proactive use of special patient notes to NHS 111 for non-verbal patients, in the same way as for patients who are approaching the end of life, to promote effective communication." (report author).

"Local authority, CCG and hospital should explore providing additional support from support workers familiar to the person for those with substantial difficulties when in hospital." (report author).

The direct provision of care

The direct provision of care for people with learning disabilities was identified in seven recommendations. This was in relation to care plans, needs assessments, and diagnostic overshadowing.

Recommendations suggested:

- Staff should be accountable for poor care provision.
- Assumptions should not be made about a person's ability to communicate and appropriate assessment must take place in order to understand this.

"Particular attention must be paid to the challenge of 'diagnostic overshadowing'". (report author).

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