



The Learning Disabilities Mortality Review  
(LeDeR) Programme

University of  
Bristol Norah  
Fry Centre for  
Disability Studies



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# Annual Report

## December 2017

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## Executive summary

## Introduction

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

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

The programme has developed a review process for the deaths of people with learning disabilities. All deaths receive an initial review; those where there are any areas of concern in relation to the care of the person who has died, or if it is felt that further learning could be gained, receive a full multi-agency review of the death. Deaths subject to the current priority review themes (aged 18-24 years or from a Black or minority ethnic background) receive multi-agency review and expert panel scrutiny. At the completion of the review, an action planning process identifies any service improvements that may be indicated.

By the end of November 2017, all but two of the 39 LeDeR Steering Groups were operational. Key processes to deliver mortality reviews of people with learning disabilities have been established, and over 1,000 local reviewers have been trained in the LeDeR methodology. The LeDeR methodology itself has been refined with routine updates twice a year, matched with amendments to training and associated materials and the LeDeR IT systems.

The programme has developed a robust quality assurance process to ensure that training is of the highest standard, is fit for purpose and ultimately delivers high quality reviews. The programme team produces targeted reports for those involved with delivering the LeDeR programme, including NHS England leads, Steering Groups, Local Area Contacts and Regional Coordinators. These reports summarise notification data, and review progress and the learning and recommendations identified in completed reviews.

The most significant challenge to programme delivery has been the timeliness with which mortality reviews have been completed, largely driven by four key factors: a) large numbers of deaths being notified before full capacity was in place locally to review them b) the low proportion of people trained in LeDeR methodology who have gone on to complete a mortality review c) trained reviewers having sufficient time away from their other duties to be able to complete a mortality review and d) the process not being formally mandated.

The programme team has been resolving these challenges in a number of ways, including the use of Key Performance Indicators; the appointment of Regional Coordinators to work with local Steering Groups; additional funding from NHS England to support local recovery plans; and the commissioning of NHS Sustainable Improvement to help address and support a reduction in the number of un-reviewed deaths, and develop a more streamlined process for the delivery of mortality reviews.

## Deaths notified to the LeDeR programme

From 1st July 2016 to 30<sup>th</sup> November 2017, 1,311 deaths were notified to the LeDeR programme. The most frequent role of those notifying a death was Learning Disability Nurse (25%), most commonly working in a Community Learning Disabilities Team.

Key information about the people with learning disabilities whose deaths were notified to the LeDeR programme includes:

- Just over half (57%) of the deaths were of males
- Most people (96%) were single
- Most people (93%) were of White ethnic background
- Just over a quarter (27%) had mild learning disabilities; 33% had moderate learning disabilities; 29% severe learning disabilities; and 11% profound or multiple learning disabilities.
- Approximately one in ten (9%) usually lived alone
- Approximately one in ten (9%) had been in an out-of-area placement.

The proportion of people with learning disabilities who died in hospital was greater (64%) than the proportion of hospital deaths in the general population (47%). Younger people with learning disabilities were more likely to die in hospital than were older people (76% of those under 24 years of age compared with 63% of those aged 65 and over); those with profound or multiple learning disabilities were more likely to die in hospital (71%) than other people with learning disabilities (59%).

The median age at death<sup>1</sup> of people with learning disabilities (aged four years and over) was 58 years (range 4-97 years). For males it was 59; for females 56. More than a quarter (28%) of deaths were of people aged under 50 years. People with profound or multiple disabilities had a median age at death of 41 years; those with mild or moderate learning disabilities had a median age at death of 63 years.

<sup>1</sup> The median age at death is the age at which exactly half the deaths were of people above that age and half were of people below that age

Less than half (44%; n=576) of deaths notified to the LeDeR programme stated a cause of death. For the remainder of the deaths notified, the exact cause of death will be confirmed to the LeDeR programme during the mortality review process itself. It is also the case that some of the preliminary causes of death given at notification, could subsequently change if, for example, a post-mortem indicates a different cause.

Almost a third of the deaths (31%) had an underlying cause related to diseases of the respiratory system. These were distributed across all age groups from aged 18 years onwards, but were more commonly given as the underlying cause of death in people between ages 25-44. The second most common category of deaths was of diseases of the circulatory system (16%). These were also distributed across all age groups but were more common in the oldest. Men were slightly more likely than women to die from circulatory disorders (18% vs. 14%).

Analysis of the individual ICD-10<sup>2</sup> codes of reported underlying causes of death indicates a significant proportion of deaths from pneumonia (16%) and aspiration pneumonia (9%).

Analysis of any conditions cited in Part I of the Medical Certificate of Cause of Deaths (MCCD) suggests causes of death broadly similar to underlying causes of death, plus sepsis (11%). People aged 25-34 were more likely to have aspiration pneumonia listed in Part I of their MCCD than were other age groups (37% vs. 24%).

<sup>2</sup> ICD-10 codes are based on the International Classification of Diseases version 10. The codes in ICD-10 classify all medical diagnoses, symptoms and procedures.

## Completed reviews of deaths of people with learning disabilities

By 30 November 2017, 103 reviews had been completed and approved by the LeDeR quality assurance process. Reviewers indicated that in 13 (13%) the person's health had been adversely affected by one or more of the following: delays in care or treatment; gaps in service provision; organisational dysfunction; or neglect or abuse. For example:

- A person was discharged home with a catheter, although the care staff had never received any training about catheter care. The person was later readmitted to hospital with possible urinary sepsis.
- For one person there was evidence of several delays in their hospital care and treatment. The patient was not monitored in terms of Modified Early Warning System (MEWS) measurements. Blood tests were not taken during their brief stay in hospital. It was also noted that there was no justification or explanation in the medical or nursing records about the course of treatment the patient received.
- For one person who could not speak up for himself, there was no professional co-ordination in relation to his long term conditions. Treatment for the patient's weight loss took months; the identification of kidney stones also took months with limited pain relief being given. Identification of a urinary infection and treatment for it with antibiotics towards the end of the patient's life could and should have been sooner; and there was no recognition before he died of pyelonephritis which was the cause of death.

The deaths of 13 people received a full multi-agency review. Three of these met the criteria for Priority Themed Review.

## Learning points and recommendations from completed reviews

From the 103 completed reviews, there were 189 learning points or recommendations identified. In each review that identified one or more learning points, the average number of learning points and/or recommendations was 2.8. Thirty-six reviews (35%) did not identify any learning.

The most commonly reported learning and recommendations were made in relation to the need for:

- a) Inter-agency collaboration and communication
- b) Awareness of the needs of people with learning disabilities
- c) The understanding and application of the Mental Capacity Act (MCA).

Most of the learning to-date echoes that of previous reports of deaths of people with learning disabilities, and the importance of addressing this cannot be over-estimated. We have a responsibility to families and others to ensure that any learning points at individual level are taken forward into relevant service improvements as appropriate.

As a result of the reviews completed, some actions have already been taken to improve service provision for people with learning disabilities. These have included, for example, strengthening discharge planning processes, and the provision of reasonable adjustments for people with learning disabilities.

National recommendations made based on completed local reviews of deaths in 2016-2017 are as follows:

1. Strengthen collaboration and information sharing, and effective communication, between different care providers or agencies.
2. Push forward the electronic integration (with appropriate security controls) of health and social care records to ensure that agencies can communicate effectively, and share relevant information in a timely way.
3. Health Action Plans, developed as part of the Learning Disabilities Annual Health Check should be shared with relevant health and social care agencies involved in supporting the person (either with consent or following the appropriate Mental Capacity Act decision-making process).
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.
5. Providers should clearly identify people requiring the provision of reasonable adjustments, record the adjustments that are required, and regularly audit their provision.
6. Mandatory learning disability awareness training should be provided to all staff, and be delivered in conjunction with people with learning disabilities and their families.
7. There should be a national focus on pneumonia and sepsis in people with learning disabilities, to raise awareness about their prevention, identification and early treatment.
8. Local services must strengthen their governance in relation to adherence to the Mental Capacity Act, 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.
9. A strategic approach is required nationally for the training of those conducting mortality reviews or investigations, with a core module about the principles of undertaking reviews or investigations, and additional tailored modules for the different mortality review or investigation methodologies.

The future focus of the LeDeR programme will be to move beyond 'learning' into 'action' to support improved service provision for meeting the health and care needs of people with learning disabilities and their families.



Chapter 1:  
**Introduction**

## Health inequalities in relation to people with learning disabilities

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

In addition, each of the six domains that are key contributors to health inequalities as identified in the Marmot Review (2010) (early child development; education; employment and working conditions; minimum income for healthy living; healthy and sustainable places to live and work; and taking a social determinants approach to prevention) are described as raising cause for concern in 2017 (Institute of Health Equity, 2017).

Health inequalities faced by people with learning disabilities have also been highlighted in recent years. Emerson and his colleagues in 2016 reported markedly poorer health for people with learning disabilities than their non-disabled peers, whilst in 2017 Osugu and colleagues concluded that in addition to having a high prevalence of diagnosed health problems, adults with learning disabilities also have a four-fold disparity in signs and symptoms that are medically unexplained.

## Inequalities in mortality of people with learning disabilities

The higher mortality rate in England for people with learning disabilities is both an outcome of health inequalities, and a health inequality itself. An overview of key reports relating to mortality of people with learning disabilities was presented in Appendix 1 of our 2015-2016 annual report (<http://www.bristol.ac.uk/sps/leder/resources/annual-reports/>). It is more than 10 years since Mencap published *Death by Indifference* (2007) highlighting 'institutional discrimination' leading to the deaths of six people with learning disabilities whilst in the care of the

NHS. In 2018 it is a decade since Sir Jonathan Michael's (2008) report 'Healthcare for all' in which he expressed shock at the 'disturbing' findings of the inquiry, and concern that the experiences of the families described in Mencap's report were by no means isolated.

Over the past few years, statistical evidence about inequalities in mortality of people with learning disabilities has been accumulating. Using data from the Clinical Practice Research Datalink database for April 2010 to March 2014 (CPRD GOLD, September 2015), Glover and colleagues at Public Health England, with the LeDeR programme, reported an all-cause standardised mortality ratio of 3.18 for people with learning disabilities (Glover et al., 2017). Their life expectancy at birth was 19.7 years lower than for people without learning disabilities. Drawing on data from the same source, Hosking et al. (2016) reported that more than a third of deaths of people with learning disabilities were potentially amenable to health care interventions. A summary of the key issues over time that have been associated with premature mortality in people with learning disabilities is presented on p.3-4 of our 2015-2016 annual report (<http://www.bristol.ac.uk/sps/leder/resources/annual-reports/>).

## National policy in relation to learning from deaths

National policy in relation to learning from deaths has been strengthened following publication of the Care Quality Commission (CQC) report 'Learning Candour and Accountability' in 2016. The report describes what the CQC found when it reviewed how NHS Trusts identify, investigate and learn from the deaths of people under their care. The report authors indicated that there was a 'common' level of acceptance and sense of inevitability when people with learning disabilities or mental illness died, and that the lack of a single framework for NHS Trusts that sets out what they need to do to maximise the learning from deaths that may be the result of problems in care was problematic. The report concluded that learning from deaths was not being given enough consideration in the NHS and

opportunities to improve care for future patients were being missed.

National Guidance on Learning from Deaths was published by the National Quality Board in March 2017. It provides a framework for NHS Trusts and NHS Foundation Trusts in England for identifying, reporting, investigating and learning from deaths of people in their care. The guidance emphasises the importance of learning from reviews of the care provided to patients who die, and that this should be integral to a provider's clinical governance and quality improvement work. It requires providers to have a clear policy for engagement with bereaved families and carers, and an updated policy on how they respond to, and learn from, deaths of patients who die. From April 2017, Trusts have been required to collect and publish on a quarterly basis specified information on deaths.

A driver for the CQC report in 2016 was the death of Connor Sparrowhawk, a young man with learning disabilities, who was under the care of Southern Health NHS Foundation Trust. A review into the circumstances at the Trust where he died revealed a very low number of investigations or reviews of deaths at the Trust (Mazars, 2015). The deaths of people with learning disabilities were therefore a particular focus of the CQC report, which is also reflected in the national guidance on Learning from Deaths. Here, it is acknowledged that the lives of people with learning disabilities often involve a complex array of service provision with multiple care and support staff. A single agency review of their death would likely fail to identify the complex interplay of circumstances leading to a person's

death, and the wide range of potentially avoidable contributory factors to their death. A cross-sector approach to reviewing deaths of people with learning disabilities is underpinned in the Learning from Deaths guidance, which states that all deaths of people with learning disabilities aged four years and older should be subject to review using LeDeR methodology.



Chapter 2:

# The LeDeR programme

## About the LeDeR programme

The LeDeR programme is delivered by the University of Bristol, and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. Work on the LeDeR programme commenced in June 2015 for an initial three-year period. The overall aims of the LeDeR programme are to support improvements in the quality of health and social care service delivery for people with learning disabilities and to help reduce premature mortality and health inequalities.

A key part of the LeDeR programme is to support local areas in England to review the deaths of people with learning disabilities aged four years and over. The programme has developed and rolled out a review process for the deaths of people with learning disabilities. By the end of 2017, the LeDeR programme was fully rolled out across England, with local Steering Groups in place, and the deaths of people with learning disabilities being reviewed in all regions.

The LeDeR programme also collates and shares anonymised information about the deaths of people with learning disabilities nationally, so that common themes, learning points and recommendations can be identified and taken forward into policy and practice improvements. These are reported in the following chapters of this report.

## Core principles and values of the programme

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

## LeDeR methodology

The LeDeR methodology is described in a flowchart in Appendix 1, a brief summary in Appendix 2, and on the LeDeR website at [www.bristol.ac.uk/sps/leder/](http://www.bristol.ac.uk/sps/leder/)

## Delivery of the LeDeR programme

In our Annual Report 2015-2016, we reported on the progress made in establishing the programme in its first year, between 1st June 2015 to 31st May 2016. This covered details about the 'set up' activities for the programme and the ways in which we worked through the challenges faced in establishing a process for local reviews of deaths. We will not repeat this information here; rather we will provide an update from June 2016 about further developments in the programme delivery.

In June 2016, a NHS England National Operational Steering Group was established, and each NHS region appointed an NHS England Regional Coordinator to guide the roll out of the LeDeR programme, across their geographical region. Each of the four NHS England regions of England established a pilot site for the LeDeR programme in 2016. The pilot sites were as follows:

- NHS England North: Cumbria and the North East
- NHS England Midlands and the East: Leicestershire, Leicester City and Rutland
- NHS England South: Wessex, Gloucester and Oxford
- NHS England London: Lambeth, Richmond, Kingston, Camden, Islington and Tower Hamlets

The lessons learnt from the pilot sites were shared at regional 'learning and sharing' events prior to the development of regional plans to deliver the wider roll-out of the programme.

By the end of November 2017, all but two of the 39 Steering Groups were operational. Key processes to deliver mortality reviews of people with learning disabilities have been established, and over 1,000 local reviewers have been trained in using the LeDeR methodology. The LeDeR methodology

itself has been refined with routine updates twice a year, matched with amendments to training and associated materials and the LeDeR IT systems. The programme has developed a robust quality assurance process to ensure that training is of the highest standard, is fit for purpose and ultimately delivers high quality reviews. The programme team produces targeted reports for those involved with delivering the LeDeR programme, including NHS England leads, Steering Groups, Local Area Contacts and Regional Coordinators. These reports summarise notification data, the progress of reviews, and the learning and recommendations identified in completed reviews.

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

- large numbers of deaths being notified before full capacity was in place locally to review them
- the low proportion of people trained in LeDeR methodology who have gone on to complete a mortality review
- trained reviewers having sufficient time away from their other duties to be able to complete a mortality review and
- the process not being formally mandated.

Some participating NHS and social care organisations have made it clear that, because of their present overstretched budgets and the

pressures on staff time, contributing to LeDeR could not be prioritised as we would all like. Nevertheless, NHS Trust level participation is expected and quarterly dashboards will be published as described in the National Guidance on Learning from Deaths - the implementation of which is overseen by NHS Improvement.

The programme team has been assessing progress in resolving these challenges with four key performance indicators, as follows:

1. The proportion of those receiving training who then collect their password to the LeDeR IT system (indicating that they are likely to be conducting a review of a death).
2. The proportion of notifications of death that are awaiting allocation from the Local Area Contact to a reviewer.
3. The proportion of deaths which have been in the LeDeR review process longer than six months.
4. The proportion of trained reviewers not aligned to a Steering Group.

Additional measures taken have been the appointment of Regional Coordinators to work with local Steering Groups; additional funding from NHS England to support local recovery plans; and NHS Sustainable Improvement has been formally commissioned to help address and support a reduction in the number of un-reviewed deaths, and develop a more streamlined process for the delivery of mortality reviews.



Chapter 3:

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

This chapter describes the demographic characteristics of the people with learning disabilities whose deaths were reviewed as part of the LeDeR programme from 1st July 2016 – 30th November 2017. It also describes information relating to their deaths.

## DEATHS NOTIFIED TO THE LeDeR PROGRAMME

### Number of deaths notified to the LeDeR programme

From 1st July 2016 to 30th November 2017, 1,311 deaths were notified to the LeDeR programme. Just under half of these (48%) were from the North of England, unsurprisingly so as the LeDeR programme was first introduced in the North. Table 3.1 presents the number of notifications of deaths of people with learning disabilities by NHS England region. Figure 1 (over-page) shows that the number of deaths notified to the programme has generally been increasing each month.

**Table 3.1: Number of notifications of deaths of people with learning disabilities by NHS England region**

| Region              | Number | %   |
|---------------------|--------|-----|
| North               | 631    | 48  |
| Midlands and East   | 241    | 18  |
| South               | 261    | 20  |
| London              | 178    | 14  |
| Total notifications | 1311   | 100 |

### Those notifying deaths

To-date, 668 different people have notified deaths to the LeDeR programme. The most frequent role of those notifying a death was Learning Disability Nurse (25%; n=168). Only three-quarters (78%; n=523) of those notifying a death included details of their employing organisation. Of these, the largest proportions worked in a Community Learning Disability Team or Community NHS Trust (38%; n=199), or in secondary or acute care (26%; n=136).

**Figure 3.1: The number of deaths notified to the LeDeR programme each month**

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

The rest of this chapter describes the demographic characteristics of the people with learning disabilities whose deaths were reviewed as part of the LeDeR programme. It also describes information relating to their deaths.

### Gender

Of the people with learning disabilities whose deaths were notified to the LeDeR programme, over half (57%; n=741<sup>3</sup>) were men.

<sup>3</sup> The gender of six people was not recorded at the time of notification.

## Marital status

Marital status was reported for 1,073 people. Of these, most people who died were single (96%). Women were more likely to have been married, divorced, widowed or separated than were men (6% vs. 2%).

## Ethnicity

The person's ethnic background was reported for 1,145 deaths notified. Almost all of these (93%) were from a White ethnic background, 4% were from an Asian background, and 4% were from other backgrounds. The proportion of people whose ethnic group was described as 'White' was higher than the 86% recorded for England and Wales as a whole (ONS, 2011).

## Severity of learning disabilities

At the point of notifying a death, the severity of a person's learning disabilities was reported for 828 people. Just over a quarter (27%) of these were known to have had mild learning disabilities; 33% had moderate learning disabilities; 29% severe learning disabilities; and 11% profound or multiple learning disabilities.

## Living alone, or away from home

Of the 1,158 people for whom the information was available at the notification of their death, 9% usually lived alone. Information about out-of-area placements was available for 1,107 deaths: of these 101 people (9%) had been in an out-of-area placement.

## Place of death

In England in 2016, 47% of deaths of the general population occurred in hospital (National End of Life Intelligence Network, 2017). Table 3.2 shows the place of death, where known at the point of

notification, for deaths notified to LeDeR. As can be seen, the proportion of people with learning disabilities who died in hospital (64%; n=801) was considerably greater than that of the general population. Younger people with learning disabilities were more likely to die in hospital than were older people, with 76% of those aged 24 and under dying in hospital (n=86) compared to 63% (n=260) of those aged 65 and older.

**Table 3.2: The place of death of people with learning disabilities**

| Place of death                        | Number | %    |
|---------------------------------------|--------|------|
| Hospital                              | 801    | 64   |
| Usual place of residence <sup>1</sup> | 373    | 30   |
| Hospice / palliative care unit        | 27     | 2    |
| Other <sup>2</sup>                    | 43     | 3    |
| Total                                 | 1244   | 100% |

<sup>1</sup> Includes own or family home, and residential or nursing home that was the person's usual address

<sup>2</sup> Includes home of relative or friend, and residential or nursing home that was not usual address

Of the 828 people for whom the severity of their learning disability was recorded at notification, those with profound or multiple learning disabilities were more likely to die in hospital (71%; n=61) than other people with learning disabilities (59%; n=412), and less likely to die at their usual place of residence (23%; n=20) compared to other people with learning disabilities (35%; n=249).

## Age at death

Of the 958 people (aged four years and over ) whose death was notified to the LeDeR programme after 1st April 2017, the median age at death was 58 years (range 4-97 years).

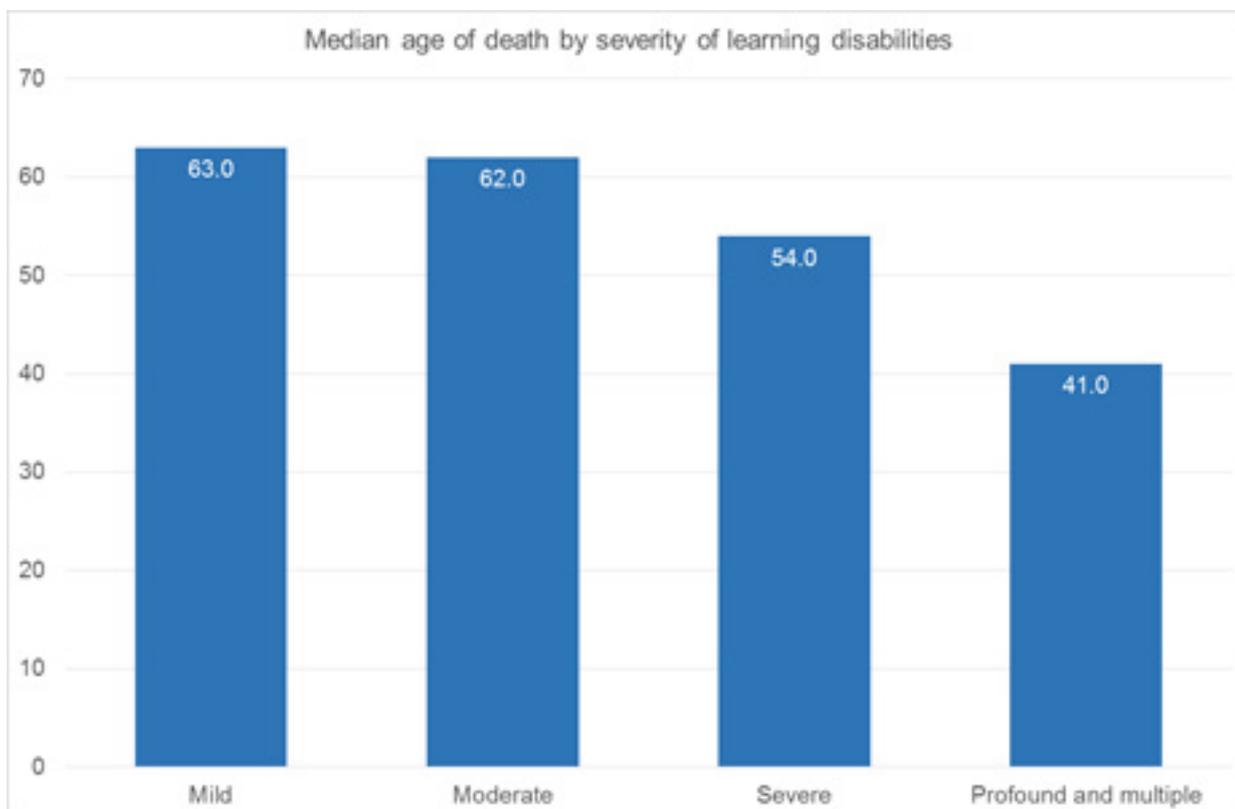
The median age at death for males aged four years and over notified to the LeDeR programme since 1st April 2017 was 59 years (range 4-92); for females it was 56 years (range 4-97).

In the general population of England and Wales in 2010, the median age at death (for all deaths including those aged 1-3 years) was 81.8 years for males and 85.3 years for females (ONS 2012 ). The difference in age at death between people with learning disabilities (aged four years and over) whose deaths were notified to LeDeR, and the general population of England and Wales (all ages, 2010 data) is therefore 22.8 years for males and 29.3 years for females.

Over a quarter (28%) of deaths notified since 1st April 2017 were of people aged under 50 years – this compares with 22% of deaths aged four years and over as reported in CIPOLD (Heslop et al. 2014), and 5% of the general population of England and Wales aged four years and over who died in 2016 (ONS 2016).

The median age at death decreased with increasing severity of a person’s learning disabilities (Figure 3.2). People with profound or multiple disabilities had a median age at death of 41 years; those with mild or moderate learning disabilities had a median age at death of 63 years. However, the median age at death for people with mild learning disabilities was still considerably less than that of people in the general population.

**Figure 3.2: Median age at death by severity of learning disabilities**



## Cause of death

Less than a half (44%; n=576) of deaths notified to the LeDeR programme stated a cause of death at the time of notification. For the remainder of the deaths notified, the exact cause of death would be confirmed during the mortality review process itself. However, it is also the case that some of the causes of death given at notification, and presented in this section, may be preliminary causes which could subsequently change if, for example, a post-mortem indicated a different cause.

Medical certificates of cause of death (MCCD) are divided into two sections, Parts I and II. Contained in Part I is the immediate cause of death, tracking the sequence of causes back to any underlying cause or causes. The World Health Organisation (WHO, 1967) defines the underlying cause of death as the 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. Part II of the MCCD is used to list other significant conditions, diseases or injuries that contributed to the death, but were not part of the direct sequence leading to death<sup>4</sup>.

<sup>4</sup> The information from the MCCD is coded using the latest International Classification of Disease (ICD) codes, to form national statistics on the causes of death of a population. The LeDeR programme has applied to NHS Digital for the ICD-10 codes of all causes of death in Parts I and II of the MCCD for those whose deaths have been notified to LeDeR. This will provide a richer, and more accurate source of information about the deaths of people with learning disabilities over time.

## Underlying cause of death

Table 3.3 presents the underlying cause of death, as categorised by ICD-10 chapters. Almost a third of the deaths (31%; n=177) had an underlying cause related to diseases of the respiratory system. The second most common ICD-10 chapter was that of diseases of the circulatory system (16%; n=95).

**Table 3.3: Underlying cause of death by ICD-10 chapter**

| Underlying cause of death  | Number | % <sup>1</sup> |
|--|--------|----------------|
| Diseases of the respiratory system                                   | 177    | 31             |
| Diseases of the circulatory system                                   | 95     | 16             |
| Neoplasms  | 55     | 10             |
| Nervous system   | 46     | 8              |
| Diseases of the digestive system                                     | 38     | 7              |
| Mental and behavioural disorders                                     | 38     | 7              |
| Congenital malformations, deformations and chromosomal abnormalities | 33     | 6              |
| Diseases of the genitourinary system                                 | 30     | 5              |
| Other underlying causes  | 64     | 11             |
| Total  | 576    | 100            |

<sup>1</sup> Percentages add to more than 100% due to rounding

Figure 3.3 shows that diseases of the respiratory system were distributed across all age groups from aged 18 years onwards, but were more commonly given as the underlying cause of death in people between ages 25-44. Diseases of the circulatory system were also distributed across all age groups, most commonly amongst the older age groups, but also amongst those aged 35 - 44.

Figure 3.3: Broad category of underlying cause of death by age group

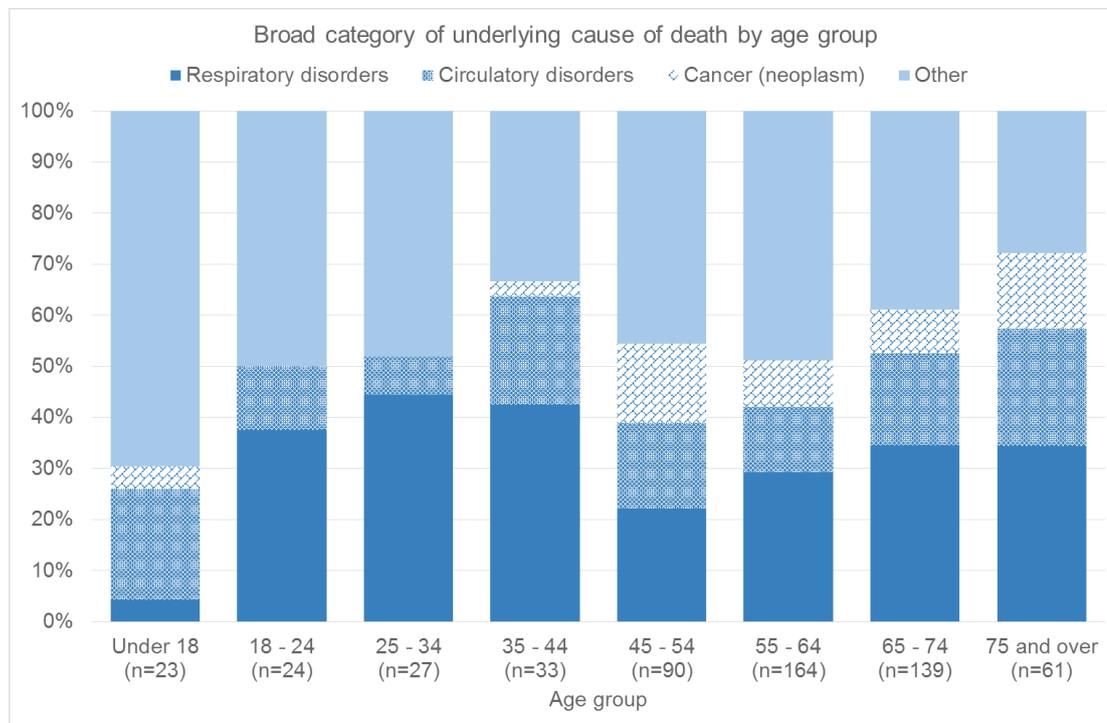


Figure 3.4 shows underlying cause of death by gender. Men were slightly more likely than women to die from circulatory disorders (18% vs. 14%), while women were slightly more likely to die from cancer (11% vs. 9%).

Figure 3.4: Underlying cause of death by gender

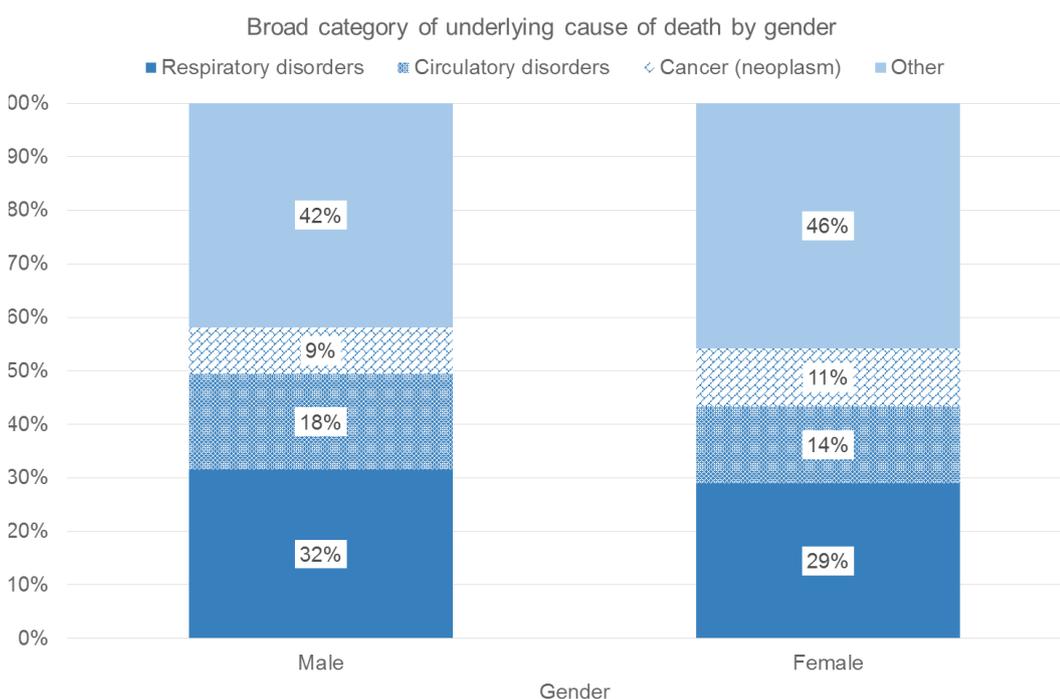


Table 3.4 provides analysis of the individual ICD-10 codes for the most commonly reported underlying causes of death. It indicates a significant proportion of deaths from pneumonia (16%; n=93) and aspiration pneumonia (9%; n=51).

**Table 3.4: Most common individual underlying causes of death by ICD-10 code**

| Underlying cause of death                                | No. | %   |
|--|-----|-----|
| Pneumonia – unspecified                                  | 93  | 16  |
| Aspiration pneumonia                                     | 51  | 9   |
| Epilepsy   | 25  | 4   |
| Dementia   | 24  | 4   |
| Down syndrome <sup>1</sup>                               | 23  | 4   |
| Total (where cause of death is reported at notification) | 576 | n/a |

## Other causes of death recorded in Part I of the MCCD

Although the underlying cause of death is the most commonly reported and used in vital statistics, it is instructive to also consider other conditions identified in the sequence from the immediate cause of death tracking back to the underlying cause of death. In part, this is because it is important to bring to light those conditions for which service improvement initiatives may be indicated, but which are not described as the underlying cause of death. In part, it is also because there is a growing body of evidence to suggest that inconsistencies and inaccuracies frequently occur in recording the cause of death of people with learning disabilities on the MCCD (Tyrer and McGrother, 2009; Glover and Ayub, 2010; Landes and Peak, 2013; Hosking et al., 2016; Trollor et al., 2017).

The conditions most frequently cited in Part I of the MCCDs of people notified to the LeDeR programme are shown in Table 3.5. While they were broadly similar to underlying causes of death (Table 3.4), the fact that sepsis is mentioned on 11% (n=66) of MCCDs is of note, given the current NHS England national sepsis action plan<sup>5</sup>.

<sup>5</sup> <https://www.england.nhs.uk/wp-content/uploads/2017/09/second-sepsis-action-plan.pdf>

**Table 3.5: Most common conditions identified as causes of death anywhere on Part 1 of MCCD**

| Most frequent causes of death                            | No. | %   |
|--|-----|-----|
| Pneumonia – unspecified                                  | 140 | 24  |
| Aspiration pneumonia                                     | 96  | 17  |
| Sepsis   | 66  | 11  |
| Dementia   | 34  | 6   |
| Epilepsy   | 28  | 5   |
| Down syndrome  | 25  | 4   |
| Cardiac arrest   | 24  | 4   |
| Respiratory infection                                    | 22  | 4   |
| Total (where cause of death is reported at notification) | 576 | n/a |

There were no significant differences between males and females in the conditions mentioned on Part 1 of the MCCD. However, people aged 25–34 were more likely to have pneumonia listed in Part I of their MCCD than were other age groups (37% vs. 24%). Other than dementia occurring in older age groups, there were no other differences in conditions listed by age group.

## COMPLETED REVIEWS OF DEATHS OF PEOPLE WITH LEARNING DISABILITIES

By 30th November 2017, 103 reviews had been completed and approved by the LeDeR quality assurance process. This section outlines some of the key findings from completed reviews.

### Involvement of someone who knew the person well

All but five reviews were completed with the assistance of someone who knew the person who had died well. Over half (56%; n=58) obtained information from staff at the home where the person lived; over a third (38%; n=39) from a family member; and a fifth from a member of a community

learning disability team (19%; n=20). Other sources of information included GP practices (17%; n=18) and social services staff (15%; n=15).

## Other investigations taking place

Reviewers reported that post-mortems were carried out on 12% (n=12) of the deaths that had completed the review process, and there was to be a Coroner's inquest into 5% (n=5) of the deaths. A further 19% (n=19) were to be subject to another investigation or review, most commonly an internal (NHS Trust) mortality review.

## Reviewers' overall assessment of the care received by the person

At the end of the review, having considered all of the information available to them, reviewers are asked to provide an overall assessment of the care provided to the individual. As Table 3.6 shows, in the majority of completed mortality reviews (79%; n=81) the care was assessed as either Grade 1 (excellent) or Grade 2 (good). A further 12% (n=12) were assessed as 'satisfactory' (Grade 3). The care received by five people (5%) was assessed as Grade 5 (falling short of best practice with the potential for learning from a fuller review of the death). The care received by one person was assessed as Grade 6 (having the potential for, or actual, adverse impact on the person).

## Aspects of care or service provision considered to have demonstrated the provision of excellent care

Almost a half (44%) of reviewers (Table 3.6) assessed the care provided to the person who had died as being 'excellent'. 'Excellent' care is described as being better than the good quality care that any patient should expect to receive. Reviewers were asked to detail any aspects of care or service provision that they considered to have demonstrated

the provision of excellent care. Generally, however, there was a lack of detail about why care was considered excellent, rather than of a good quality. For example, one reviewer commented that excellent care had been provided because 'there were numerous experts involved' in the person's care, without specifying exactly what it was that made this excellent care. Another commented that the sister of the person who had died described her care as 'exemplary' and that it had supported her sister to have 'a dignified and happy end of life', but had not explained what it was that made the care 'exemplary'.

Similarly, other examples of excellent care were related to the provision of reasonable adjustments that health services have a duty to provide under the Equality Act 2010. One reviewer described excellent care as being related to the support provided to the brother and sister-in-law of a person who died, noting that both were partially sighted and were encouraged to stay in hospital with their relative in her final weeks; the relatives had told the reviewer that they had felt well supported during and after their relative's death. Another reviewer described excellent care as being provided by the hospital learning disability liaison nurse, reporting that 'when Gerald<sup>6</sup> was not able to be safely supported at home, they worked with him to find out what was most important to him (his wife and football on TV) and ensured he had both of these with him on the ward. Gerald found this very reassuring and it greatly improved his experience'.

Additionally, a few reviewers described excellent care in relation to the home environment in which the person had lived, one reviewer noting that 'the care home went above caring', and describing it as a 'family' where the person appeared to be 'loved as well as cared for.'

Moving forward, we are hopeful that reviewers will be able to identify more tangible examples of excellent care that can be shared with all agencies, and adopted and implemented as appropriate.

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<sup>6</sup> All names have been changed to protect confidentiality

## Aspects of care or service provision which may have adversely affected the person

Reviewers indicated that 13 (13%) people's health had been adversely affected by one or more of the following: delays in care or treatment; gaps in service provision; organisational dysfunction; or neglect or abuse. For example, in relation to one person the reviewer noted:

Discharged home with a catheter and the care staff had never had any training on catheter care. Nick was later readmitted to hospital with possible urinary

sepsis. The failure to liaise with carers about their knowledge and skills in catheter care contributed to an unsafe discharge, readmission and rapid decline in health.

Another reviewer noted:

*'There was evidence to indicate several omissions occurred within the hospital, which caused delays in care and treatment provided to Marlon. He was not monitored in terms of Modified Early Warning System (MEWS) measurements, and no blood tests were taken*

**Table 3.6: Reviewers' overall assessment of the care received by the person**

|   | Overall assessment  | No. | %    |
|---|---|-----|------|
| 1 | This was excellent care and met current best practice   | 45  | 44   |
| 2 | This was good care, which fell short of current best practice in only one minor area  | 36  | 35   |
| 3 | This was satisfactory care, falling short of current best practice in two or more minor areas, but no significant learning would result from a fuller review of the death   | 12  | 12   |
| 4 | Care fell short of current best practice in one or more significant areas, but this is not considered to have had the potential for adverse impact on the person and no significant learning could result from a fuller review of the death | 1   | 1    |
| 5 | Care fell short of current best practice in one or more significant areas, although this is not considered to have had the potential for adverse impact on the person, some learning could result from a fuller review of the death         | 5   | 5    |
| 6 | Care fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person   | 1   | 1    |
|   | No grading given  | 3   | 3    |
|   | Total   | 103 | 100% |

during his brief stay in hospital - there was no documentation in the medical or nursing records to justify these courses of action.

Marlon was extremely distressed due to his skin condition and the pain associated with this. He was given analgesia and subsequently slept for long periods of time, during which he was not disturbed to be offered diet and fluids. It is likely the staff thought they were acting in his best interest by not disturbing him. While it was unlikely that even with optimal management this death could have been prevented, it should be noted that i) the omission of one dose of [medicine] is unlikely to have prevented the fatal pulmonary embolism, although it may have done so and ii) sepsis or dehydration could have contributed to the development of a pulmonary embolism in this patient. A lack of investigations performed on admission meant that these conditions, if present, were not diagnosed or treated.'

In relation to another death, the reviewer commented:

*'This was a gentleman who could not advocate for himself. He was under the care of a urologist when a child, this stopped at age 18. For 8 years he had no follow up care and during this time he developed a large kidney stone which was the main cause of his death. There was*

*no professional co-ordination in relation to his long-term conditions; the treatment of his weight loss took months; the identification of his kidney stones took months; limited pain relief was given, the identification of urinary infection and commencement on antibiotics towards the end of his life could have been done sooner; and there was no recognition of pyelonephritis which was the cause of death.'*

## **Progression to multi-agency review**

If there are areas of concern identified about the death, or if it is felt that a fuller review could lead to improved practice, a more in-depth or multi-agency review takes place. This involves the range of agencies that have been supporting the person who has died, (e.g. health and social care staff). Multi-agency reviews are also undertaken when people who died meet the Priority Themed Review criteria (Appendix 2).

The deaths of 13 people received a full multi-agency review: three of these met the criteria for Priority Themed Review.

Actions taken in relation to learning and recommendations from completed reviews are described in the following chapter.



Chapter 4:

# Learning and recommendations from completed reviews

The LeDeR programme's success will be determined by the ability of commissioners and providers of services to convert learning and recommendations from completed reviews into service improvements. As such, at the end of the initial and multi-agency review forms there is space for reviewers to identify learning and recommendations (from initial reviews) and action points (from multi-agency reviews). These are collated by the LeDeR team, and reported back to Steering Groups, Regional Coordinators and Regional Leads via the routine reporting systems of the programme.

## Overall themes identified as learning points or recommendations

Of the 103 completed reviews, 67 identified a total of 189 learning points<sup>7</sup>. Thirty-six reviews (35%) did not explicitly identify any learning, the remainder identified between 1-21. Overall, the average was 2.8 learning points in each review.

The most commonly reported learning and recommendations were made in relation to the need for:

- a) Inter-agency collaboration, including communication
- b) Awareness of the needs of people with learning disabilities
- c) The understanding and application of the Mental Capacity Act (MCA)

It should be noted that two learning points referred to evidence of good practice and the opportunity for others to learn from positive experiences, both in relation to inter-agency communication.

## Inter-agency collaboration, including communication

The largest category of learnings or recommendations related to collaboration and communication between agencies and, while some elements of good practice were identified,

concerns about a lack of coordination and sharing of information between care providers were apparent.

Good practice identified included one reviewer reporting<sup>8</sup>:

'The family actively participated in discussions with the multidisciplinary team and in planning Jenny's end of life care. This was facilitated by a high level of communication between the many acute, critical care, palliative care and community professionals involved in her care as well as by a clear and organised plan for managing her transfer back to the care home and her management there.'

Another reviewer commented:

*'There was excellent use of the traffic light assessment tool and full involvement of the LD Liaison Nurses, to ensure Frank's needs were met. All referrals within the hospital were accepted promptly and all the teams within the hospital appeared to work well together to provide consistent and timely care for him.'*

Reviews of other deaths, however, identified considerable scope for improvements in inter-agency collaboration and communication, particularly in relation to communication involving residential or care homes and health professionals.

For example, one reviewer commented:

*'A shortfall was liaison between the GP, community teams, and the residential home staff. None of the care home staff were involved in Best Interest decision meetings, so there were delays in getting the right information and sharing expertise.'*

Another reviewer reported that although the person with learning disabilities relied on those who knew his individual and communication patterns well in order identify his needs, they had no way of sharing this key knowledge with others supporting and caring for him.

A range of recommendations was made in relation to improving interagency collaboration and communication. These included:

<sup>7</sup> For simplicity, 'learnings' and 'learning points' are used in this chapter to cover learning points, recommendations and action plans.

<sup>8</sup> Learning and recommendations have been edited from the originals submitted by reviewers.

- Ensuring that a health passport is created if a person with learning disabilities does not already have one when admitted to hospital.
- A&E department to improve signage about expected waiting times and what to do if condition deteriorates whilst waiting to be seen.
- Poor or unsafe discharges from hospital to be addressed at quality review group meetings.
- Address the need for good healthcare co-ordination for people with learning disabilities.
- GP practices to follow-up the reason for non-attendance at Annual Health Checks, and inform the Community Learning Disabilities Team about those known to the service and not responding to invitations.

## Awareness of the needs of people with learning disabilities among health and social care providers

The second largest category of the learning and recommendations related to raising awareness about the needs of people with learning disabilities. Training needs across a spectrum of roles were noted, including those working in A&E, the local authority, acute services, care providers and primary care.

Recommendations for training included general awareness about the health needs of people with learning disabilities. Several reviewers commented on the importance of health care staff being aware of behaviour as a means of communication, for example:<sup>9</sup>

*'Acute services need to be supported in recognising the needs of patients with learning disabilities in their care, particularly people with communication difficulties who may present with certain behaviours as a mechanism to communicate.'*

<sup>9</sup> Learning and recommendations have been edited from the originals submitted by reviewers.

Another reviewer notes the need to:

*'Ensure that front line practitioners are aware that changes in behaviour and mood can be a sign of an underlying medical condition.'*

Reviews of deaths also identified the need for a greater awareness of the health needs of people with learning disabilities to be embedded within the healthcare system, with one reviewer commenting:

*'GPs may benefit from a reminder of the system within Community Learning Disability Teams which identifies people who have Down's Syndrome and their need to be assessed for early onset dementia.'*

Another reviewer noted that:

*'There is still a need for GP practices and clinical leads to be made aware of the importance of full annual health checks for people with learning disabilities.'*

Raising the awareness of paid care staff about supporting people receiving palliative care was also identified as a learning point, with one reviewer recommending a discussion with the local contract monitoring team about supporting end of life awareness training in residential and supported living services.

Some of the lack of awareness of the needs of people with learning disabilities was underpinned by staff not being able to easily access a record of their specific needs. One reviewer noted that the person with learning disabilities had had anxieties about accessing services where there were stairs, and as a consequence attendance at appointments was not consistent. They felt that had this been recorded, reasonable adjustments could have been made.

Another reviewer recommended that

*'If a patient who is flagged on a register does not attend their appointments, they should be followed up to establish if reasonable adjustments are required, and not discharged first.'*

## Better understanding and application of the Mental Capacity Act

The third largest category of the learning and recommendations related to the need for a better understanding and application of the Mental Capacity Act (MCA). Reviewers identified problems with the level of knowledge about the MCA by a range of professionals, and concerns about capacity assessments not being undertaken, the Best Interests process not being followed, and Deprivation of Liberty Safeguards (DOLS) not being applied. For example, in relation to one person, the reviewer noted:

*'Several references to lack of capacity in hospital records but no evidence of a capacity assessment in records. A consent form for the procedure did indicate a lack of capacity through a tick system but was not backed up with a full capacity assessment - a capacity assessment form was on file but not completed.'*

*'Additionally, there is evidence of close and continuous supervision at times during Ashley's admission to hospital whilst awaiting the procedure, but no evidence of a consideration for DOLs authorisation, despite a number of entries in the notes identifying that she did not have capacity. Without a formal assessment it is difficult to identify what the statement 'lacks capacity' relates to.'*

The learning and recommendations from the review related to the need for improved training about all aspects of the Mental Capacity Act and DOLS.

In the review of another death, the reviewer noted concerns about the validity of a tenancy agreement for a person's supported living accommodation as the person had not had a capacity assessment and was thought unlikely to have understood the terms of the agreement. A recommendation was made for social care annual reviews to consider the validity of tenancy agreements as part of a check on adherence to the MCA.

## From 'learning' to action

The importance of addressing the learning from individual deaths cannot be over-estimated. This is a crucial aspect of the service improvement cycle, and we have a responsibility to families and others to ensure that any learning points at individual level are taken forward into relevant service improvements as appropriate.

Several examples of actions resulting from the reviews of deaths of people with learning disabilities have been given.

For example, a couple of reviews reported concerns about unsafe discharges of people with learning disabilities. Actions taken include one hospital trust reviewing safeguarding procedures in relation to discharge planning for patients with learning disabilities, and another hospital adding a 'catheter prompt' on their discharge planning forms to ensure that any changes to the level of support that may be required for a person are identified early, and carers properly trained in any new aspects of the person's care.

In relation to the provision of reasonable adjustments for people with learning disabilities in hospital, one trust has now raised this with ward staff to ensure that 'reasonable adjustment care plans' are in place for all patients with learning disabilities.

To address poor inter-agency communication, one area has been discussing with the Clinical Commissioning Group the need to fund specialist support for people with learning disabilities when admitted to hospital in an emergency. In relation to another death that highlighted concerns about inter-agency communication, a multiagency meeting was held to review joint working arrangements.

More general learning disability awareness training has also been delivered to a range of professionals following the findings of the LeDeR review. In addition, one reviewer recorded that a hospital had now identified two members of staff to be learning disability, autism and 'hidden' disability champions, and that a folder containing advice and support about caring for people with learning disabilities is kept at the nursing station on the ward.

## The need for further action

There is, at present, a raft of initiatives in place to raise awareness of the needs of people with learning disabilities, and improve the delivery of health and care services. Some of these are:

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

However, most of the learning from mortality reviews presented in this annual report echoes

that of previous reports of deaths of people with learning disabilities, with the same issues repeatedly identified as problematic over the past decade or so. For example:

- Mencap's Death by Indifference (2007) reported that many healthcare professionals 'do not understand much about learning disability' (p.19), and 'do not understand the law around capacity and consent to treatment' (p.21).
- In 2008, Sir Jonathan Michael concluded that 'the evidence shows a significant gap between policy, the law and the delivery of effective health services for people with learning disabilities' (Michael 2008, p.53), and recommended 'improve[d] data, communication and cross-boundary partnership working' (p.54).
- In 2013, CIPOLD recommended 'Clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems'; 'Reasonable adjustments required by, and provided to, individuals, to be audited annually'; and 'Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care' (Heslop et al. p.108).

These same issues are being raised as problematic in LeDeR reviews some 10 years after coming to public attention in Death by Indifference.

A model that can be helpful when thinking about the development of expertise in supporting people with learning disabilities is that of 'Conscious Competence', developed in the 1970s. According to the model, we move through four stages as we develop expertise (see Figure 4.1):

- Unconsciously incompetent – we don't know that we don't have this expertise, or that we need to learn it.
- Consciously incompetent – we know that we don't have this expertise.
- Consciously competent – we know that we have this expertise.
- Unconsciously competent – we don't know that we have this expertise (it just comes naturally).

People do not usually make an effortless, smooth transition from one stage to another: different strategies are needed in the move between stages, and in making recommendations from the completed LeDeR reviews we need to bear this in mind. For example, delivering training about the requirements of the Mental Capacity Act may be necessary for those who are ‘unconsciously incompetent’, but other professionals may benefit more from the opportunity to apply the learning to their work setting, and develop their skills and expertise through joint working and reflecting on their practice.

## **Recommendations for action**

Based on the evidence from completed LeDeR mortality reviews, we make a number of important and key recommendations. These are summarised in Table 4.1 and more fully explained below.

## **Inter-agency collaboration and communication**

Evidence suggests that in general, interagency collaboration is perceived by professionals, those using services and their families, as having a beneficial impact and outcome (Cooper et al., 2016). Facilitative factors for interagency collaboration and communication are:

- ✓ Good working relationships, including a commitment from all staff to work together, trust and mutual respect across agencies, and shared understandings
- ✓ Transparent and constant communication between agencies
- ✓ Adequate funding, staffing and time, and the presence of a key worker or care co-ordinator
- ✓ Strong leadership and clear lines of accountability.(Atkinson et al. 2007).

**Table 4.1: Summary of recommendations**

|    | <b>Recommendation</b>  | <b>Responsible agency</b>                 |
|----|--|---|
| 1. | Strengthen collaboration and information sharing, and effective communication, between different care providers or agencies.   | Commissioners                             |
| 2. | Push forward the electronic integration (with appropriate security controls) of health and social care records to ensure that agencies can communicate effectively, and share relevant information in a timely way.  | NHS England                               |
| 3. | Health Action Plans, developed as part of the Learning Disabilities Annual Health Check should be shared with relevant health and social care agencies involved in supporting the person (either with consent or following the appropriate Mental Capacity Act decision-making process).                   | NHS England<br>Commissioners<br>Providers |
| 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.  | Commissioners                             |
| 5. | Providers should clearly identify people requiring the provision of reasonable adjustments, record the adjustments that are required, and regularly audit their provision.   | Providers                                 |
| 6. | Mandatory learning disability awareness training should be provided to all staff, delivered in conjunction with people with learning disabilities and their families.  | Commissioners<br>Providers                |
| 7. | There should be a national focus on pneumonia and sepsis in people with learning disabilities, to raise awareness about their prevention, identification and early treatment.  | NHS England                               |
| 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.   | Commissioners<br>Providers                |
| 9. | A strategic approach is required nationally for the training of those conducting mortality reviews or investigations, with a core module about the principles of undertaking reviews or investigations, and additional tailored modules for the different mortality review or investigation methodologies. | NHS England                               |

Our first recommendation is therefore to **strengthen collaboration and information sharing, and effective communication, between different care providers or agencies**. There may be a number of ways of addressing this, but one approach could be for health and social care agencies to appoint a person with leadership responsibility for interagency collaboration and communication. As a matter of priority, this role-holder should develop, monitor and audit the effectiveness of their policy and procedures for interagency collaboration and communication; and train all staff members about good practice in interagency communication.

Our second recommendation is to **push forward the electronic integration (with appropriate security controls) of health and social care records to ensure that agencies can communicate effectively, and share relevant information in a timely way**. People with learning disabilities are often in touch with several health and care providers, but the records are usually siloed in different systems, or in multiple sets of paper records. We suggest that NHS England work with NHS Digital and the Professional Records Standards Body to develop information standards relating to the multi-agency care of people with learning disabilities, and others, that will enable professionals

to share high quality digital care records and promote their widespread use in health and social care systems.

Our third recommendation is that **Health Action Plans developed as part of the Learning Disabilities Annual Health Check should be shared with relevant health and social care agencies involved in supporting the person (either with consent or following the appropriate Mental Capacity Act decision-making process)**. The learning disabilities annual health check scheme is a voluntary reward programme for primary medical services. Under the scheme for 2017-18, GP practices are encouraged to produce a register of all patients aged 14 years or over with learning disabilities; offer all the patients on this register an annual health check and perform the health check where the patient agrees to this; and offer all the patients on the register a Health Action Plan and produce the Health Action Plan where the patient agrees to this. A National Electronic Health Check clinical template for people with learning disabilities is currently under development (see: <https://www.england.nhs.uk/wp-content/uploads/2017/05/nat-elec-health-check-ld-clinical-template.pdf>); we feel that a strong steer is required from NHS England for this to be shared (with patient consent) across relevant health and social care agencies involved in supporting the person.

Our fourth recommendation is that **all people with learning disabilities with two or more long-term conditions (related to either physical or mental health) should have a local, named health care coordinator**. The National Institute for Clinical Excellence (NICE) quality standard (QS142) for people with learning disabilities and a serious mental illness, is that they should have a key worker to improve care coordination and help services to communicate clearly with people with learning disabilities and their family members and carers. Current NHS England recommendations are that commissioners should extend the offer of a named local care coordinator to all people with learning disabilities and/or autism who have a mental health condition or behaviour that challenges

(LGA, ADASS, NHSE, 2015; Public Health England, 2017). In the light of the extent to which potentially avoidable contributory factors leading to death are related to poor inter-agency collaboration and communication, we do not believe that this is sufficient. Rather, we suggest that parity is upheld between the impact of physical and mental health conditions, and that any person with learning disabilities with two or more long-term conditions, of whatever nature, is supported in managing their overall healthcare needs with a local, named health care coordinator.

### **Awareness of the needs of people with learning disabilities**

Our fifth, sixth and seventh recommendations focus on improving an awareness about the needs of people with learning disabilities. As already mentioned above, there is already positive work in progress to raise awareness of the needs of people with learning disabilities, and improve the delivery of health and care services; when fully introduced and implemented, these will make a positive contribution.

Our **fifth recommendation is that providers clearly identify people requiring the provision of reasonable adjustments, record the adjustments that are required, and regularly audit their provision**. The mortality reviews provided patchy evidence about the provision of reasonable adjustments for people with learning disabilities, although this is a statutory requirement for health and care services.

**Our sixth recommendation is that mandatory learning disability awareness training should be provided to all staff, delivered in conjunction with people with learning disabilities and their families**. Evidence from the mortality reviews suggested that the influence of all staff, not just 'front line' staff providing health or social care, was important and could make a difference to the outcomes for people with learning disabilities. Office secretaries, outpatient booking clerks, cleaners and meal attendants could all be influential, and it is equally important that they receive learning disability awareness training.

**Our seventh recommendation is for a national focus on pneumonia and sepsis in people with learning disabilities, to raise awareness about their prevention, identification and early treatment.** The issue of the high rate of deaths potentially amenable to good quality care also deserves attention. Here, bacterial pneumonia, aspiration pneumonia and sepsis are key contributors. Identifying the early signs of illness is essential, and carers must be alert to how these diseases may present, take all preventative measures, and be proactive in seeking timely medical attention.

### **The understanding and application of the Mental Capacity Act (MCA)**

Our eighth recommendation is 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 findings from the LeDeR mortality reviews echo the House of Lords post-legislative scrutiny of the Mental Capacity Act conclusion that there is a lack of awareness and understanding about the MCA, principally within the health and social care sectors. They commented:

*‘For many who are expected to comply with the Act it appears to be an optional add-on, far from being central to their working lives...the prevailing cultures of paternalism (in health) and risk-aversion (in social care) have prevented the Act from becoming widely known or embedded....The duties imposed by the Act are not widely followed.’ (p.6).*

### **The process of undertaking mortality reviews**

Our ninth recommendation is that **a strategic approach is taken nationally for training those conducting mortality reviews or investigations, with a core module about the principles of undertaking reviews or investigations, and additional tailored modules for the different mortality review or investigation methodologies.** This supports, but extends, the Department of Health and Social Care (DHSC) mandate to Health Education England (HEE) which states the requirement for HEE to work with the Healthcare Safety Investigation Branch and providers to develop approaches to ensuring that ‘staff have the capability and capacity to carry out good investigations of deaths and write good reports, with a focus on these leading to improvements in care.’ (DHSC p.16).

### **The future focus of the LeDeR programme**

The focus of the LeDeR programme over the coming year will be to follow-up on the actions that are proposed in mortality reviews. We need to ensure that we move beyond ‘learning’ into a more proactive approach to meeting the health needs of people with learning disabilities, which requires targeted action and commitment to improve service delivery where required.

A model for how this could be realised was shared by Emily Lauer, the lead for mortality reviews of people with learning disabilities at Massachusetts USA. She spoke at a series of workshops for LeDeR Steering Group members in England in June 2017, to share some of the actions that have been implemented in various States in the USA and how their effectiveness is being monitored. Her presentations can be viewed at: <https://www.youtube.com/watch?v=lw-coxPOI> and <https://www.youtube.com/watch?v=nBnjwi-5sEk>



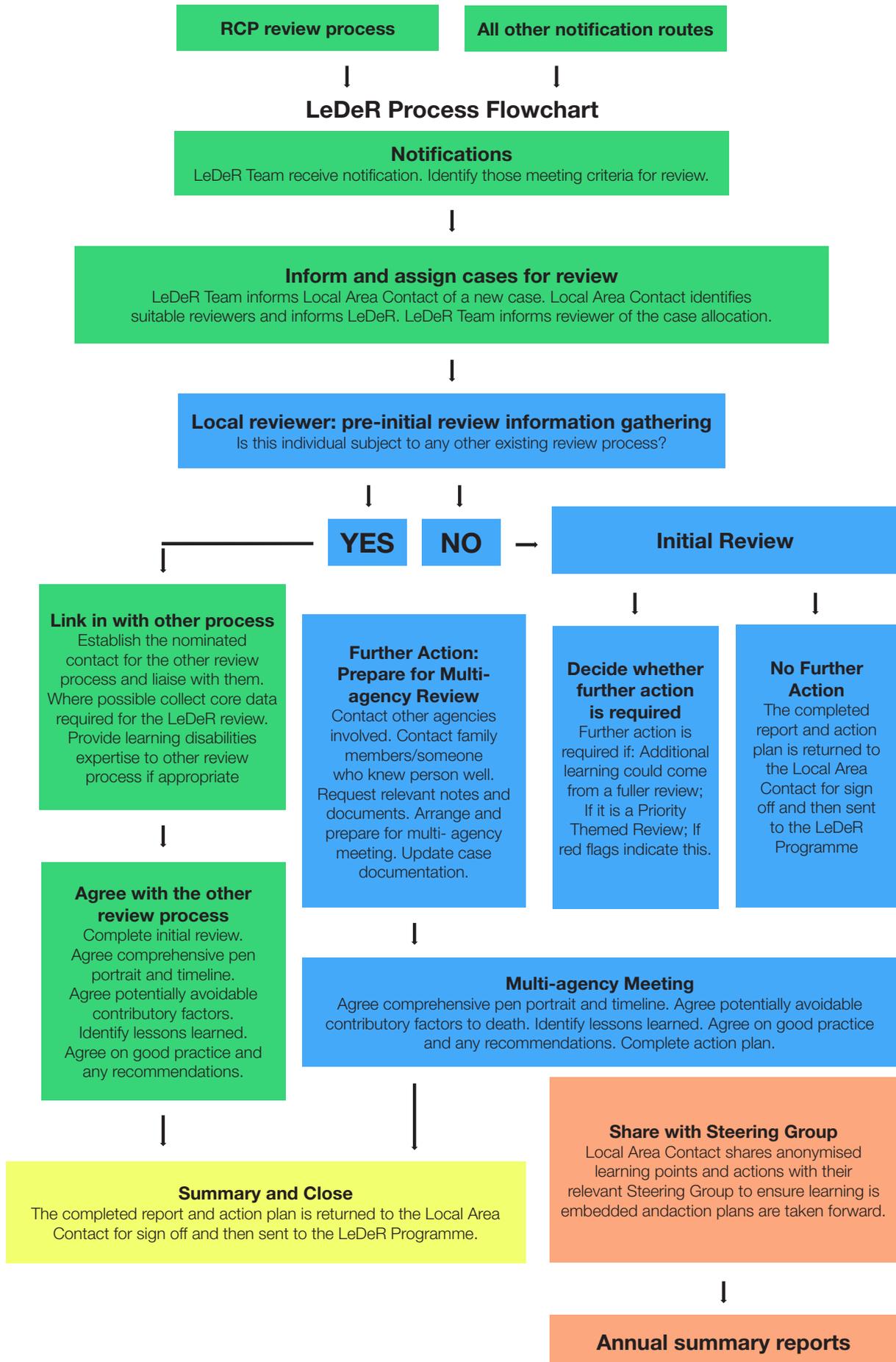
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# Appendices

# Appendix 1: LeDeR process flowchart



## Appendix 2: LeDeR methodology

### Notification of a death

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

### Initial review

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

### Multi-agency Review of a death

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

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

### Action planning process

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

### Priority Theme Reviews

The Priority Theme Review aspect of the LeDeR programme examines the deaths of a subset of people with learning disabilities in more detail. Two themes are currently under scrutiny:

- Deaths of people aged 18 to 24 years
- Deaths of adults and children from a Black or Minority Ethnic group.

Deaths subject to Priority Themed Review receive an initial and full multi-agency review. The review documentation is anonymised by the LeDeR team, and then sent to Priority Themed Review panel members for further comment. Comments from the panels are collated by the LeDeR team and incorporated into the completed review documentation.

### The LeDeR quality assurance process

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

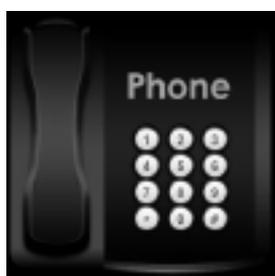
## Appendix 3: Acknowledgements

There are many people whom we would like to thank for their support and help with implementing the LeDeR programme. In particular, we would like to thank:

- NHS England, particularly Dr Dominic Slowie, Matthew Fagg, Crispin Hebron, John Trevains and Kevin Elliott
- HQIP
- The Regional Coordinators: Maria Foster, Emily Handley, Robert Tunmore, and Louisa Whit
- Members of the Independent Advisory Group chaired by Dr Dominic Slowie
- Members of the LeDeR Programme Steering Group chaired by Professor Peter Fleming
- Members of the LeDeR Programme Advisory Groups
- The National Valuing Families Forum
- All of the family members and people with learning disabilities who have attended any of the LeDeR consultation events
- Those working to implement the LeDeR programme as Steering Group members, Local Area Contacts, and reviewers

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# Thank-you for reading this report.



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**[www.bristol.ac.uk/sps/leder](http://www.bristol.ac.uk/sps/leder)**



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