



Department
of Health &
Social Care

The Government response to the third annual Learning Disabilities Mortality Review (LeDeR) Programme report

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Foreword

The Learning Disability Mortality Review (LeDeR) programme was established in 2015 to drive improvements in the quality of health and social care for people with a learning disability and to help reduce premature mortality and health inequalities. Now, in 2020, the programme provides the largest body of evidence on deaths of people with a learning disability at an individual level anywhere in the world. The deaths reviewed by the LeDeR programme show that, compared with the general population, the median age of death is 23 years younger for men and 27 years younger for women. Whilst some learning disabilities are associated with conditions with lower life expectancy, it does not explain why all people with a learning disability are more likely to die prematurely and, in some cases, of entirely preventable causes.

Of course, each and every death that might have been prevented is a tragedy and we must not compound that tragedy by failing to learn the lessons that might improve the care that is provided in the future. The LeDeR programme was commissioned to learn from these deaths. Through LeDeR, we are revealing and challenging the often deep-rooted systematic and cultural issues that exist within the health and social care system that prevent people with a learning disability accessing the high-quality care they deserve. For example, the programme has highlighted important issues such as the use of Do Not Attempt Cardio-Pulmonary Resuscitation (DNA CPR) for people with a learning disability, resulting in urgent action being taken to prevent this happening in future.

LeDeR review findings have also drawn attention to significant concerns such as the need for learning disability awareness training for staff in health and social care settings. In November 2019, I was pleased to set out our commitment to introduce the Oliver McGowan mandatory training in learning disability and autism for all health and social care workers. I consider this an important move to help address the cultural issues identified by the LeDeR reviews, improving understanding of the needs of people with a learning disability and autistic people amongst the staff who care for them. The training is named in memory of Oliver McGowan, in recognition of his story, his family's tireless campaigning for better training for staff, and to remember him and others whose lives were cut tragically short.

We are already working with Health Education England and Skills for Care to develop and test a standardised training package during 2020/21, backed by a £1.4 million investment. Testing will take place in a variety of health and social care settings, to help shape how training will be rolled out and delivered in the future. Implementing mandatory training will mark a step change across the health and care sector and demonstrates the commitment this government has made to improving outcomes for people with a learning disability and autistic people.

The third annual report of the LeDeR programme was published in May 2019. It once again provided a reminder that much more remains to be done to ensure that everybody who has a learning disability receives care that meets their needs. This document sets out our response to that report and shows how we have begun to act on the recommendations to deliver the improvements to services that will make a real and significant difference to people's lives. It is vital that we listen to feedback from people affected by this work and ensure that we take an approach which enables us to gather real learning and insight from the reviews that we put into practice. I will keep an open mind about how to best improve the LeDeR programme in future to enable us to achieve this.

The University of Bristol has played a hugely important role since the beginning of the LeDeR programme, setting out the learning and recommendations from the LeDeR reviews in their annual reports. We are grateful for the significant contribution they have made. I also want to take this opportunity to reiterate our ongoing commitment to the mortality reviews themselves being undertaken as set out in the NHS's Long Term Plan.

We must ensure we continue to build on the momentum established in the first years of the LeDeR process. Since the start of the LeDeR programme, nearly 3,200 reviews have been completed and over 2,700 are currently in progress. And while increases in the number of reviews carried out is welcome, we acknowledge that the pace with which reviews are conducted still needs to increase further.

In May 2019, NHS England announced an additional £5 million investment to address the number of unreviewed cases and to increase the pace at which cases are allocated and reviewed. As the LeDeR process has been embedded, the number of notifications to review boards has increased. While both the number of reviews overall and the number of reviews waiting to be allocated have gone up, the measures put in place to ensure progress have reduced the proportion of unallocated reviews. By the end of 2020, we expect that every CCG will be able to complete all their reviews within six months of a notification of a death as the required standard.

But we know there is still more to do. We are committed to improving transparency about the support delivered for people with a learning disability and/or autism. To do this, NHS England will publish information on the progress of LeDeR reviews as part of the learning disability and autism dashboard. The LeDeR programme also complements other important work to improve the lives of people with a learning disability, such as Transforming Care and implementing Building the Right Support, which focuses on reducing the number of people with learning disabilities and/or autistic people who are inpatients in mental health hospitals, and who instead should be supported to live full lives in their community.

I continue to be overawed by the commitment and passion I see from people with lived experience, their families and carers, and our partners across the health and care sector, to improve outcomes for people with learning disabilities and autistic people. Every single

untimely death is a death too many but I am confident that by working together we can continue to learn lessons and act now to address glaring inequalities.

1. Introduction

- 1.1 This report set out the Government's response to recommendations made in the third annual Learning Disabilities Mortality Review (LeDeR) report.
- 1.2 The LeDeR programme was established in May 2015 to drive improvements in health and social care for people with learning disabilities and to help reduce premature mortality and health inequalities in this population.
- 1.3 The LeDeR programme uses the information and learning gained from completed reviews to develop national recommendations for the Department of Health and Social Care and partners across the health and social care systems in policy development. The programme published its [third annual report](#) in May 2019, which covered the period 1 July 2016 to 31 December 2018, and had a particular focus on deaths reported in 2018.
- 1.4 This response articulates where the Government has accepted the recommendations, fully or in part. It also provides an update on the actions identified in the [Government's response to the second annual LeDeR report \(published 2018\)](#). This response, coupled with NHS England's [Action from Learning report](#) (May 2019), shows the action being taken on the recommendations to deliver the improvements to services that will make a real and significant difference to people's lives.
- 1.5 The issues and causes of death identified within the third annual report reflect the many challenges that people with learning disabilities continue to face, and how we must do more to support them to live well in their local communities.
- 1.6 Nearly half of the deaths reviewed showed that people with learning disabilities received care that met or exceeded good practice. However, this should be the expectation for all and it is concerning that some people with learning disabilities are continuing to receive care that sometimes falls so short of good practice that it significantly impacts on their wellbeing, or directly contributes towards their cause of death.
- 1.7 The report also noted that, compared to the general population, the median age of death is 23 years younger for men with a learning disability and 27 years younger for women. This again demonstrates much more needs to be done to ensure people with learning disabilities can access the best possible quality care and support.
- 1.8 Based on the evidence from completed LeDeR reviews, the third annual LeDeR report makes twelve recommendations for the education, and health and care

systems. Here, we set out our response to each of the recommendations. NHS England and NHS Improvement have already developed an action plan in response to the LeDeR report, which is set out in their 'Action from Learning' report.

2. Responding to the Third LeDeR Report's Recommendations

Recommendation one: National oversight leads for the LeDeR Programme

Consider designating national leads within NHS England and local authority social care to continue active centralised oversight of the LeDeR programme.

- 2.1 We agree that it is essential to have focussed national leadership within the health and care sectors to ensure the LeDeR programme is successful and well embedded across the system. The diverse nature of the health and care sectors means different approaches are required to ensure oversight is maintained everywhere.
- 2.2 The LeDeR report highlighted variations and inconsistencies locally in conducting reviews of deaths, putting the core principles and values of the LeDeR programme at risk. To mitigate this risk, the report recommended national leads within NHS England and local authority social care provide oversight, to maintain the specific LeDeR approach to reviewing deaths, ensure the quality of completed reviews, and translate learning into action.
- 2.3 With regards to centralised oversight within the health sector, there is dedicated resource, leadership and oversight of the LeDeR programme on a national level in NHS England and NHS Improvement. The [NHS Long Term Plan](#) set out the NHS's commitment to accelerate the LeDeR initiative, and to continue to fund the LeDeR programme.
- 2.4 Due to the diverse nature of the social care sector, a different approach is required to maintain effective central oversight of the LeDeR programme. The Association of Directors of Adult Social Care (ADASS) and the Local Government Association (LGA) are the organisations that jointly provide oversight of the LeDeR programme in the social care sector.
- 2.5 Both the LGA and ADASS are independent organisations. The LGA is a membership organisation that represents the interests of the local government sector as a whole. ADASS are a charity that are the independent voice of adult social care. As each local authority is autonomous, it would not be feasible to appoint an overarching national lead for local authorities as they would not have the ability to direct action across all local authorities. However, both the LGA and

ADASS work closely with NHS England to support programmes of work to improve outcomes for people with a learning disability and autistic people nationally and are committed to promoting improvement in this area.

- 2.6 Additionally, ADASS have a Learning Disability and Autism Policy Network. The overall aim of this network is to focus on individuals and communities to ensure they experience high quality care and support, less inequality and improved outcomes. They also have a general overview of work in support of the LeDeR programme.
- 2.7 While the structures are different across the health and care sectors, these approaches enable NHS England and the LGA and ADASS to maintain oversight of the LeDeR programme across the country.

Recommendation two: Support for Clinical Commissioning Groups

NHS England to support Clinical Commissioning Groups to ensure the timely completion of mortality reviews to the recognised standard.

- 2.8 We agree that NHS England should continue to support Clinical Commissioning Groups (CCGs) to complete mortality reviews to the recognised standard. The LeDeR programme was established to drive improvements in health and social care delivery for people with learning disabilities. It is essential that CCGs are well supported to conduct reviews in a timely way, to a high standard, to ensure that learning from deaths are captured and acted upon. The LeDeR programme now provides the largest body of evidence of deaths of people with a learning disability at an individual level anywhere in the world.
- 2.9 The LeDeR report highlighted ongoing and significant problems with the timeliness with which reviews of deaths were taking place.
- 2.10 CCGs, working with their local authority and NHS partners, have now made significant progress towards completing LeDeR reviews in a timely way. Whilst the increase in the number of reviews carried out is welcome, we acknowledge that more needs to be done.
- 2.11 During 2019/20, NHS England have put in place a number of measures to support CCGs to discharge their duties in relation to the timely completion of LeDeR reviews. These include:

- Contracting with a Commissioning Support Unit to provide additional capacity to support CCGs.
- Providing £5 million of additional funding to CCGs and the North of England Commissioning Support Unit (NECS) to enable them to develop systems and processes to increase the pace at which cases are allocated and reviewed. This funding is being used to develop a dedicated workforce to carry out reviews, and to develop systems and processes to embed quality improvement activity across the health and social care system. More than 2,000 experts have now been trained to undertake reviews.

2.12 [NHS operational planning and contracting guidance for 2019/2020](#) sets out clear guidance to CCGs in terms of their responsibilities for LeDeR. CCGs are now expected to publish annual local LeDeR reports, which describe the progress they have made in completing reviews and how the learning has been translated into service improvements.

2.13 There is ongoing work, and additional funding, by NHS England to support CCGs to complete mortality reviews in a timely manner. NHS England expect that, by the end of 2020, every CCG will be in a position to conclude all reviews within 6 months, apart from where other investigatory processes mean a longer interval is appropriate. At the time of writing, nearly 3,200 reviews have now been completed and over 2,700 are currently in progress. As a proportion of the total number of notifications to the Programme unallocated reviews had reduced from 39% in November 2018 to 28% in December 2019. However, we are not complacent and acknowledge that the pace with which reviews are conducted needs to increase.

2.14 NHS England will help to continue to drive the pace of completion by publishing data, as part of a forthcoming learning disability and autism dashboard, on the progress of LeDeR reviews, to maximise transparency.

Action	Description	Owner	By when?
1	NHS England to publish information on the completion of LeDeR reviews as part of the learning disability and autism dashboard.	NHS England	NHS England will publish data each quarter. We anticipate that the first publication will be in February 2020.

Recommendation three: Identifying young people at transition

There should be a clear national statement that describes, and references to relevant legislation, the differences in terminology between education, and health and social care so that 'learning disability' has a common understanding across each sector and between children's and adults' services.

- 2.15 We agree that it is essential for a common understanding of 'learning disability' to be shared across education, and health and social care. The use of clear, shared terminology between services helps to minimise challenges for individuals moving between organisations, such as during the transition from children to adult services. There are already existing definitions of 'learning disability' which can be used to ensure a common understanding of the term. We support the use of these existing definitions across education, and health and social care.
- 2.16 The LeDeR report highlighted that some reviews of deaths noted problems with health and social care systems identifying young people with learning disabilities at transition from children's services to adults' services. Some of the problems stemmed from the use of different terminology within education and health and social care settings.
- 2.17 [The Children's and Families Act 2014](#) (Part 3, section 20) sets out the definitions of learning difficulty and learning disability for children and young people, and both the Act and the [SEND Code of Practice](#) give guidance to health and social care, education, and local authorities to make sure that such children and young people are properly supported.
- 2.18 There are existing definitions that are widely used and accepted by health and social care professionals, such as that provided by ['Valuing People: a new strategy for learning disability for the 21st century'](#), with this definition including the presence of lower intellectual ability, significant impairment of social or adaptive functioning and onset in childhood.
- 2.19 To support local LeDeR reviews, the central LeDeR programme has developed a [briefing paper](#) setting out the current most recognised definition of what it is to have a learning disability, as well as some groups who do not fall within this definition. This will provide a useful resource to others who may be working with or involved in the care of people with learning disabilities.
- 2.20 The existing resources set out above should be used to ensure a shared understanding of the definition of 'learning disability' across sectors. We support

the use of these definitions and resources being adopted across education, and health and social care.

Recommendation four: Identifying people from BAME groups

Clinical Commissioning Groups and local LeDeR steering groups to use local population demographic data to compare trends within the population of people with learning disabilities. They should be able to evidence whether the number of deaths of people from Black, Asian and Minority Ethnic groups notified to LeDeR are representative of that area and use the findings to take appropriate action.

- 2.21 We agree it is important that CCGs and local LeDeR steering groups are able to identify themes, including demographic trends and potential under-representation at a local level, and address the themes and recommendations identified in the mortality reviews. Such intelligence can help inform evidence based local policy and help ensure such local inequalities are tackled.
- 2.22 The Programme’s findings suggest adults with learning disabilities from Black, Asian and Minority Ethnic (BAME) groups may be under-represented in notifications of deaths to LeDeR, and there is a higher proportion of adults and children from BAME groups who have severe or profound multiple learning disabilities. This highlights a wider issue about having better information about local BAME communities to inform service improvements and local planning.
- 2.23 [The 2019/20 NHS Operational planning and contracting guidance for CCGs](#) requires that each CCG develop and maintain an action plan to address the themes and learning from reviews and publish an annual report. We would expect the annual report to identify and address inequalities within the context of the local demographic profile of people with a learning disability.

Action	Description	Owner	By when?
2	CCGs will produce an annual LeDeR report each year and the themes from these will be considered as part of the NHS England Action from Learning report.	NHS England	The next Action from Learning report will be published in late Spring 2020.

Recommendation five: Listening to families

The Department of Health and Social Care and NHS England to support national mortality review programmes to work with 'Ask, Listen, Do' and jointly develop and share guidelines that provide a routine opportunity for any family to raise any concerns about their relative's death.

- 2.24 The 'Ask Listen Do' programme supports organisations to learn from and improve the experiences of people with a learning disability, autism or both. The programme supports their families and carers when giving feedback, raising a concern, or making a complaint. It also makes it easier for paid carers to give feedback, raise concerns and complain. Resources have been developed by NHS England and delivered in partnership with health and social care partners. The resources can be found on NHS England's website.
- 2.25 We are supportive of and continue to encourage widespread use of the existing 'Ask Listen Do' [resources](#). It is essential that organisations are able to learn from, and improve the experiences, of people with a learning disability and autistic people and their families and carers, when giving feedback, raising a concern or making a complaint. Additionally, the introduction of medical examiners will enable relatives to identify concerns about a death not subject to a coroner's review.
- 2.26 The report highlighted that one in ten reviews noted some concerns had been raised in relation to the person's death, with almost half of the concerns raised by family members. This indicates a need for families to be routinely invited to be involved in a review of a death of their relative and for them to be able to raise any concerns as well as share what worked well in their relative's care.
- 2.27 The report acknowledged that not all mortality review processes provide this opportunity to families, putting some at a disadvantage.
- 2.28 As set out in NHS England's 'Action from Learning' report, the involvement of families has been a core principle and value at the heart of the LeDeR programme to maximise the learning from deaths and ensure the rights and needs of families are appropriately considered. As well as involving bereaved families throughout the learning into action work, NHS England and NHS Improvement have commissioned the learning disability charity, Respond, to work with a group of bereaved family carers of people with a learning disability to develop resources to enhance the experiences of families involved in LeDeR reviews. The group is currently developing resources for LeDeR reviewers and CCG staff, as well as resources for bereaved families.

Recommendation six: Priority programmes of work needed

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.

- 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.
- 2.32 Action from Learning also provided examples of local changes that have been made to services so far, as well as highlighting the extensive work which is happening nationally in response to common themes raised through LeDeR reviews across the country.

Action	Description	Owner	By when?
3	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.	NHS England	The next Action on Learning report will be published in late Spring 2020.

Recommendation seven: Service and care co-ordination

Guidance continues to be needed on care co-ordination and information sharing in relation to people with learning disabilities, at individual and strategic levels.

- 2.33 The LeDeR report highlighted that reviews are continuing to identify inadequacies in the co-ordination of care and appropriate information sharing as potential contributory factors to deaths.
- 2.34 We recognise the importance of care co-ordination and information sharing to improve outcomes for people with learning disabilities.
- 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 (IPC) 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	Description	Owner	By when?
4	DHSC to publish an evidence review of care co-ordination for people with learning disability, focused on health and wellbeing	DHSC	Summer 2020

Recommendations eight and nine: Transition from children's to adults' services

Shortfalls in adherence to the statutory guidance in the Special Educational Needs and Disability (SEND) Code of Practice in relation to identifying and sharing information about people with learning disabilities approaching transition, transition planning and care co-ordination must be addressed.

- 2.38 We agree that effective and supported transition from children’s SEND services to adult social care is an important part in enabling young people with SEND to thrive in adult life. The SEND Code of Practice is an integral part of this process, and the Department for Education have committed to review the Code and engage with stakeholders to best support these objectives.
- 2.39 [The SEND Code of Practice](#) states that education, health and care plans must include clear preparation for adulthood outcomes from the time a young person turns 14, with consideration of how an effective transition to adult services can be supported where appropriate.
- 2.40 In autumn 2019, the Government instructed officials to undertake a root-and-branch review of the SEND system, including the support that is provided to children and their families. The Government had already given a commitment to review and update the SEND Code of Practice. During 2020, that work – including building on extensive engagement with stakeholders already underway – will provide opportunities to bring greater focus to tackling the risk factors for early mortality.

Action	Description	Owner	By when?
5	The Department for Education will build on ongoing work to review and update the SEND Code of Practice, including through extensive engagement with stakeholders, to bring greater focus to tackling risk factors for early mortality.	Department for Education	During 2020-21

The Royal College of Paediatrics and Child Health to be asked to identify and publish case examples of best practice and effective, active transition planning and implementation for people with learning disabilities as they move from children’s to adults’ health services.

- 2.41 We agree that it is important to share best practice relating to transitions from children's to adults' health services. The Royal College of Paediatrics and Child Health have published case examples of best practice of transitional care. They will continue to update and share effective case studies online.

- 2.42 The LeDeR report set out that problems with transition planning for those moving from children’s to adult services was identified in a number of reviews, with fragmented care and a lack of clarity about decision making.

- 2.43 In 2017, the Royal College of Paediatrics and Child Health published [Facing the Future: Standards for children with ongoing health needs](#), which describes the need for a designated person to coordinate developmentally appropriate transitional care between children and adult services. This standard aims to ensure that children and young people undergo a smooth transfer to the appropriate adult service, with concerns around continuing care reduced, and support given to the young person developing autonomy in managing their condition.

- 2.44 The College has also collected a range of best practice examples in its online [hub](#), that highlight examples of good practice from across the UK.

- 2.45 The College has brought together a range of [resources](#) including webinars and signposting to other organisations for children with SENDs and disability. This is in addition to its [engagement work](#) with children and young people on their experience of the health transition processes, and what they determine a good transition to look like.

- 2.46 The College is a partner in the Health Education England Programme ‘Disability Matters’, a free e-learning resource developed to support those who work, volunteer, or engage with disabled children and young people, of which there are a wide range of resources available on [transition](#).

Action	Description	Owner	By when?
6	The Royal College of Paediatrics and Child Health will continue to work with its specialty	Royal College of Paediatrics and Child Health	Ongoing

	colleagues on collecting and sharing best practice examples via its website.		
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Recommendations ten, eleven and twelve: Addressing bias

Recommendation ten: The Department of Health and Social Care, working with a range of agencies and the Royal Colleges are to issue guidance for doctors that ‘learning disabilities’ should never be an acceptable rationale for a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order, or to be described as the underlying or only cause of death on Part I of the Medical Certificate Cause of Death.

Recommendation eleven: Medical Examiners to be asked to raise and discuss with clinicians any instances of unconscious bias they or families identify e.g. in recording ‘learning disabilities’ as the rationale for DNACPR orders or where it is described as the cause of death.

Recommendation twelve: The Care Quality Commission (CQC) to be asked to identify and review DNACPR orders and Treatment Escalation Personal Plans (TEPPs) relating to people with learning disabilities at inspection visits. Any issues identified should be raised with the provider for action and resolution.

- 2.47 We agree that DNACPR orders must be free from any discrimination, including disability discrimination. The findings of the third annual report were completely unacceptable and action was taken immediately to address this.
- 2.48 In the reviews covered by the third LeDeR annual report, where a DNACPR order was in place, the majority of these were appropriate, correctly completed and followed. Nineteen reviews reported that the terms “learning disabilities” or “Down’s Syndrome” were given as the rationale for a DNACPR order.
- 2.49 With regards to Recommendation 10, we want to be very clear that people with learning disabilities have the same right to enjoy a meaningful life as anyone, and treatment decisions must be based on objective information and never on assumptions about the person’s quality of life. [Guidance](#) on decisions relating to cardiopulmonary resuscitation from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing are clear that

decisions about DNACPR must be free from any discrimination, including disability discrimination.

"Decisions about CPR must be free from any discrimination, for example, in respect of a disability. A best-interests decision about CPR is unique to each person and is to be guided by the quality of future life that the person themselves would regard as acceptable, or, in the case of children, take into account the views of the child and parents."

- 2.50 To reinforce this, in May 2019 NHS England and NHS Improvement's national medical director, Professor Stephen Powis, wrote to senior doctors and nurses to remind them and their staff of the guidance on the use of DNACPR and that the recording of DNACPR should reflect this guidance.
- 2.51 The report also highlighted 15 people with learning disabilities who had their underlying cause of death coded as 'developmental disorder of scholastic skills, unspecified' – a commonly used code for learning disabilities.
- 2.52 Learning disabilities are not fatal conditions and should never be used as a cause of death. Accurate recording of the cause of death as part of the process of learning is one of the ways to reduce premature mortality for people with learning disabilities. Professor Powis' letter therefore also reinforced the need for doctors to adhere to [guidance on completing medical certificates of cause of death](#).

Taken from the guidance on completing medical certifications of cause of death in England and Wales

"Long-term physical disabilities, mental health problems and learning difficulties (also known as learning disabilities or intellectual disabilities) are rarely sufficient medical explanation of the death in themselves. If such a condition is considered to be relevant, the more immediate mechanism(s) or train of events leading to death must be made clear... A description such as 'learning difficulties' should not be the only cause of death."

- 2.53 The LeDeR report suggests that such attitudes may be symptomatic of a wider disregard for people with learning disabilities, and that increased scrutiny is needed of where these attitudes are exhibited in the care of people with learning disabilities, with a role for NHS England, the Royal Colleges, and CQC in this process.
- 2.54 Our plans to introduce mandatory learning disability and autism training for all health and care staff will address unconscious attitudes and ensure people with learning disabilities receive compassionate and informed care.

- 2.55 With regards to Recommendation 11, we agree that the role of a medical examiner will help to contribute to the learnings from death process.
- 2.56 The role of a medical examiner is planned to become statutory in April 2021, subject to parliamentary time, however the non-statutory medical examiner system is already being rolled out across England from April 2019.
- 2.57 Medical examiners are required to complete core e-learning and face to face training to undertake the role of a medical examiner. Both the core e-learning and the face to face training includes reference to the Learning from Deaths case record review process. Medical examiners are required to support this process by signposting cases they scrutinise for a case record review as required, which would include deaths of people with learning disabilities.
- 2.58 Medical examiner scrutiny must comprise of a medical record review; reviewing the proposed causes of death; whether the coroner needs to be notified with the qualified attending practitioner; and asking the bereaved whether they have questions about the cause or circumstances of death or concerns about the care before death.
- 2.59 In England, medical examiners have important links to Learning from Deaths, highlighting cases for review and ensuring they are flagged to the NHS trust mortality lead and/or to the relevant mortality review programme.
- 2.60 Therefore, we believe that Recommendation 11 is sufficiently fulfilled by existing processes for the medical examiner, as they review the proposed cause of death and where appropriate escalate to a coroner, as well as engaging with families about concerns regarding cause of death.
- 2.61 With regards to Recommendation 12, CQC's current inspection approach prompts inspectors to review records relevant to a person's care and treatment, including DNACPR and TEPPs where applicable. Where shortfalls in the quality and safety of care are identified, CQC will take appropriate regulatory action to encourage and ensure action is taken by providers to meet the requirements of legislation and improve care.

Action	Description	Owner	By when?
7	CQC is reviewing its current relevant inspector guidance with a view to updating and expanding the guidance available and	CQC	October 2020

The Government response to the third annual Learning Disabilities Mortality Review (LeDeR) Programme report

	promoting its particular importance for people with a learning disability.		
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3. The Government's response to the second annual LeDeR report - update report

Introduction

- 3.1 The LeDeR programme published its [second annual report](#) in May 2018, summarising findings from death notifications between July 2016 and November 2017. It provided nine key recommendations based on the evidence from the 103 reviews completed within the reporting period.
- 3.2 The report identified poor care co-ordination and collaboration between agencies, a lack of understanding of the needs of people with learning disabilities, and a lack of understanding of the Mental Capacity Act. In 13% of the completed reviews the person's death was affected by delays in care or treatment, gaps in service provision, organisational dysfunction, or neglect or abuse.
- 3.3 In September 2018, the Government published its [response](#) to the report, accepting all of the report's recommendations and setting out a series of actions for the Department of Health and Social Care, NHS England, NHS Improvement, NHS Digital, Health Education England, Public Health England and the Care Quality Commission to implement these recommendations.
- 3.4 The following is an update on the progress that the Department of Health and Social Care has made to implement the actions assigned to it, since publication of the Government's response. Annex B sets out the current status of all the actions identified in the Government's response.

Progress on actions

Care Co-ordination

To disseminate the evaluation of the Named Social Worker model.

- 3.5 To help localities develop approaches to providing a single named contact to co-ordinate care and help navigate clients through services, we committed to disseminating the evaluation of the Named Social Worker Model.

- 3.6 We commissioned the Named Social Worker programme to develop an understanding of how having a named social worker could contribute to people with learning disabilities, autism, or mental health needs having a better experience of services and achieving better outcomes. The project looked specifically at how they and their family could be in control of decisions about their future and supported to live with dignity and independence.
- 3.7 The programme supported nine local authorities to pilot a named social worker approach. This tested what difference it would make (and what it would look like in practice) for people to have an allocated social worker who could build a meaningful relationship with them, coordinate support in a holistic and person-centred way, and be an advocate within the system. Evidence from the programme evaluation conducted by the Social Care Institute for Excellence (SCIE) concluded the approaches taken by pilot sites have had a positive impact on people who use services, the workforce, and the wider system.
- 3.8 [Evaluation findings, lessons learnt and tools](#) to support other areas interested in developing and implementing similar models were published online in July 2018. SCIE also hosted a webinar in July 2018 to share what had been learnt through the programme and to explore what the findings meant for other local areas looking to take on similar approaches.

To undertake a rapid review of best practice in care co-ordination.

- 3.9 Effective co-ordination of care across and within health and care services is one of the key factors in improving quality of life and health and wellbeing of people with learning disabilities.
- 3.10 As highlighted elsewhere in this report, we are currently working with the Institute of Public Care at Oxford Brookes University to gather together existing evidence and case studies of care co-ordination for people with learning disabilities.
- 3.11 This action has not been completed in the anticipated timeframe. 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. 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. As above, we have committed to publishing the evidence review by the summer, this year.

Education and Training

To complete a consultation on proposals for mandatory learning disability awareness training.

- 3.12 One of the more commonly reported learning points in local LeDeR reviews is the need for learning disability awareness training for staff in health and social care settings. Evidence from mortality reviews suggested that all staff, not just front-line staff providing health or social care, should receive training and this could make a real difference to outcomes for people with learning disabilities.
- 3.13 In the Government's response to the second annual LeDeR report we committed to consulting on options for delivering mandatory learning disability training, delivered in conjunction with people with lived experience. The [consultation](#), which ran for 10 weeks, opened on 13 February 2019. We received over 5000 responses to the consultation, with many from people with lived experience and their families and carers, signalling a high level of interest in the consultation and in improving the training health and social care staff receive.
- 3.14 We published our response to the consultation, '[Right to be Heard](#)', on 5 November 2019. The overall response to the consultation showed very wide support for the introduction of mandatory training in recognition that this would improve health and wellbeing outcomes and help to ensure that people with learning disabilities and autistic people would have a more positive experience of health and social care services.
- 3.15 The consultation response also set out our plans on how we will implement our proposals, working with partners and stakeholders.
- 3.16 A key aspect of the response is to develop and trial during 2020/21, a package of learning disability and autism training in a range of health and social settings. We will run a series of trials during 2020/21, to help us better understand the implications of mandatory training and the associated costs. The training will be named in memory of Oliver McGowan, in recognition of his story, his family's tireless campaigning for better training for staff, and to remember him and others whose lives were cut tragically short. It will involve people with lived experience, will be evaluated thoroughly. The evaluation of the trials will inform a wider roll-out of training.
- 3.17 We are also working with professional bodies, regulators, employers and other organisations to determine the best way to achieve a core curriculum so that in future all professionals will, before starting their career or through continuing

professional development, undertake learning disability and autism training that is consistent across education and training curricula.

- 3.18 We intend mandating the Oliver McGowan training in learning disability and autism through changes to the [Health and Social Care Act 2008 \(Regulated Activities\) Regulations 2014](#). This will require all NHS and social care providers who carry out regulated activities to ensure that their staff have achieved the learning outcomes relevant to their role as described in the [Core Capabilities Framework for Supporting People with a Learning Disability](#), and the [Core Capabilities Framework for Supporting Autistic People](#). We will also explore options for extending the scope to non-regulated staff in social care, taking account of the new burdens assessment test for Local Authority commissioned services, as well as the evidence from the trials we will undertake in social care settings.

To write to providers and employers promoting the Learning Disability Core Skills Education and Training Framework and reminding them of their responsibilities in respect of training.

- 3.19 We wanted to make sure that there was greater understanding and awareness of the Learning Disability Core Skills Education and Training Framework (which has been subsequently updated and republished as the [Core Capabilities Framework for Supporting People with a Learning Disability](#)), in advance of any introduction of mandatory training and that employers, in meeting their responsibilities to train their staff, were choosing training that was consistent with the Framework.
- 3.20 In November 2018 the Minister for Care Caroline Dinéage, NHS Medical Director Professor Stephen Powis, and Chief Nursing Officer Professor Jane Cummings, [wrote](#) to professional organisations and all employers to remind them of their statutory responsibilities in terms of staff training and how they could use the Framework to help them meet those responsibilities.

To commission Skills for Care to undertake a comprehensive skills and training audit of the social care workforce.

- 3.21 We commissioned Skills for Care to undertake a learning disability skills audit to assess the extent to which staff working with people with learning disabilities in social care settings had received training. The findings would then help to support the roll out of mandatory training.
- 3.22 In order to determine the levels of education and training, as well as gaps and challenges for the social care workforce, Skills for Care undertook an analysis of workforce data using the adult social care workforce data set, as well as a

research evidence review and engagement with the sector. Quantitative data will also be used from the National Minimum Data set. The report is now being finalised by Skills for Care and will be published by summer 2020.

Action	Description	Owner	By when?
8	Skills for Care to publish a comprehensive skills and training audit of the social care workforce, which will be used to inform the development of the mandatory training programme.	Skills for Care	Summer 2020

National Mental Capacity Forum

To update on progress on the National Mental Capacity Forum.

- 3.23 The report highlighted the need for better understanding and application of the Mental Capacity Act (MCA) as LeDeR reviewers had identified problems with the level of knowledge about the MCA amongst professionals, as well as concerns about capacity assessments not being undertaken, and best interests processes not being followed.
- 3.24 The National Mental Capacity Forum works with stakeholders from health and social care, together with those from other sectors, such as the financial and legal sectors, the police and housing, to identify local actions to improve awareness, understanding, and implementation of the MCA.
- 3.25 In July 2019, the Chair of the Forum, Baroness Finlay of Llandaff, published her [third annual report for 2018-19](#), to highlight the Forum's progress against priority actions from the last year, and outlined its priorities for the coming year.

Annex A: Summary of actions in response to recommendations in the third annual LeDeR report

Action	LeDeR recommendation	Description	Owner	By when?
1	NHS England to support Clinical Commissioning Groups to ensure the timely completion of mortality reviews to the recognised standard.	NHS England to publish information on the progress of LeDeR reviews as part of the learning disability and autism dashboard.	NHS England	Data will be published each quarter, with the expectation of the first publication in February 2020.
2	Clinical Commissioning Groups and local LeDeR steering groups to use local population demographic data to compare trends within the population of people with learning disabilities. They should be able to evidence whether the number of deaths of people from Black, Asian and Minority Ethnic groups notified to LeDeR are representative of that area and use the findings to take appropriate action.	CCGs will produce an annual LeDeR report each year, and the themes from these will be considered as part of the NHS England Action from Learning report.	NHS England	To be included in Action from Learning reports.
3	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	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	NHS England	To be published in late Spring 2020.

Action	LeDeR recommendation	Description	Owner	By when?
	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.	reviews.		
4	Guidance continues to be needed on care co-ordination and information sharing in relation to people with learning disabilities, at individual and strategic levels.	DHSC to publish an evidence review of care co-ordination for people with learning disability, focused on health and wellbeing	DHSC	Summer 2020
5	Shortfalls in adherence to the statutory guidance in the Special Educational Needs and Disability (SEND) Code of Practice in relation to identifying and sharing information about people with learning disabilities approaching transition, transition planning and care co-ordination must be addressed.	The Department for Education will build on ongoing work to review and update the SEND Code of Practice, including through extensive engagement with stakeholders, to bring greater focus to tackling risk factors for early mortality.	Department for Education	During 2020-21
6	The Royal College of Paediatrics and Child Health to be asked to identify and publish case examples of best practice and effective, active transition planning and implementation for people with learning disabilities as they move from children's to	The Royal College of Paediatrics and Child Health will continue to work with its specialty colleagues on collecting and sharing these best practice examples via its website.	Royal College of Paediatrics and Child Health	Ongoing

Action	LeDeR recommendation	Description	Owner	By when?
	adults' health services.			
7	The Care Quality Commission (CQC) to be asked to identify and review DNACPR orders and Treatment Escalation Personal Plans (TEPPs) relating to people with learning disabilities at inspection visits. Any issues identified should be raised with the provider for action and resolution.	CQC is reviewing its current relevant inspector guidance with a view to updating and expanding the guidance available and promoting its particular importance for people with a learning disability.	Care Quality Commission	October 2020
8	To commission Skills for Care to undertake a comprehensive skills and training audit of the social care workforce. [Identified in the second annual LeDeR report]	Skills for Care to publish a comprehensive skills and training audit of the social care workforce, which will be used to inform the development of the mandatory training programme.	Skills for Care	Summer 2020

Annex B: Update on actions set out in the government's response to the 2018 LeDeR report

Action	Description	Owner	By when?	Status
1	Report on accessible information in learning disability services in NHS Trusts.	Care Quality Commission/ NHS Improvement	October 2019	Complete NHSI report available here . CQC reported on accessible information in learning disability services in NHS Trusts in October 2019's State of Care publication, within the Equality in Health and Social Care chapter.
2	NHS England to report annually to the Department of Health and Social Care on progress made on the learning into action workstream regarding improvements in interagency communication achieved through local action.	NHS England	March 2019	Complete – detailed in the Action from Learning report 2019.
3	Update to the Department of Health and Social Care on progress made in Flagging and Summary Care Record (SCR) development work.	NHS Digital/ NHS England	November 2018	Complete – Commitments made and published in the NHS Long Term Plan.

Action	Description	Owner	By when?	Status
4	Once testing is complete, NHS England and NHS Digital to develop clear guidance on how the 'flagging system' will support clinical practice. NHS England to continue to support the use of additional information in the SCR through the Annual Health Check Programme.	NHS England/ NHS Digital	March 2020	Testing is complete and NHS England are piloting in two areas. Information from NHS Digital on reasonable adjustment flags is available here .
5	NHS England to review how Local Health and Care Record Exemplars (LHCRES) could better integrate the approach to sharing of pertinent information between health and care providers for people with a learning disability.	NHS England	March 2019	Complete – Local Health Care Record Exemplars are sharing information across our health and care services to support the needs of each individual. This is being trialled in local transformation priorities such as cancer in Yorkshire and Humber, and frailty in greater Manchester.
6	NHS England to report progress on uptake of Annual Health Checks to the Department of Health and	NHS England	Annually	Complete - annual health check data is published here and was assessed via the CCG IAF.

Action	Description	Owner	By when?	Status
	Social Care via CCG Improvement and Assessment Framework (CCG IAF).			
7	Disseminate the evaluation of the Named Social Worker model.	Department of Health and Social Care	July 2018	Complete – detailed in this report.
8	Undertake a rapid review of best practice in care co-ordination / key working for people with learning disability, focused on health and wellbeing, to inform guidance for the NHS on care co-ordination.	Department of Health and Social Care	March 2019	DHSC will publish an evidence review of care co-ordination for people with learning disability, focused on health and wellbeing by Summer 2020. 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.
9	Publish update to the Department of Health and Social Care on progress made in adding a reasonable adjustment flag to the SCR application	NHS England	February 2019	NHS England and NHS Digital have built a reasonable adjustment flag in the NHS Spine to enable health and care professionals to record, share and view patients' reasonable adjustments across the NHS. This enables staff and services to carry out this anticipatory duty wherever the patient is treated. NHS England will provide an update following completion of the pilots.
10	Implement NHS Digital Reasonable	NHS Digital/ NHS England	2020	Testing is complete and NHS Digital is trialling the reasonable adjustment flag

Action	Description	Owner	By when?	Status
	Adjustment Project roll-out and as part of this, align with the LHCREs to ensure the same information is being used in both.			for patients with a learning disability in Gloucester and Devon to test the technology behind the flag and gather feedback from staff, patients and carers.
11	The Department of Health and Social Care, in conjunction with partners, will complete a consultation on proposals for mandatory learning disability awareness training.	Department of Health and Social Care	March 2019	<p>Complete – published as ‘The Right to Be Heard’ – response to consultation on mandatory training. The government has committed to introducing the Oliver McGowan mandatory training in learning disability and autism, for health and social care workers.</p> <p>We are already working with Health Education England and Skills for Care to develop and test a standardised training package during 2020/21, backed by a £1.4 million investment. Testing will take place in a variety of health and social care settings, to help shape how training will be rolled out and delivered in the future.</p>
12	NHS England and the Department of Health and Social Care to write to providers and employers promoting the Learning Disability Core Skills Education and Training Framework	NHS England/ Department of Health and Social Care	September 2018	Complete – joint letter sent by the Minister for Care, NHS England's medical director and director of nursing to promote awareness of the Framework and greater consistency in workforce development and the design and delivery of education and training programmes.

Action	Description	Owner	By when?	Status
	and reminding them of responsibilities in respect of training.			
13	Health Education England to develop and publish a Tier 1 training offer.	Health Education England	2019	Tier 1 e-learning is due to be completed in April. Health Education England will be asking mandatory training Providers to use it as part of the trials for the mandatory training programme.
14	Health Education England to audit provision of learning disability training.	Health Education England	June 2021	<p>The Oliver McGowan mandatory training in Learning disability and autism, will be trialled during 2020, the outcome of those trials will inform how we should record and monitor mandatory training during the roll out phase.</p> <p>DHSC and Skills for Care are working on a complementary piece of work to audit the skills and training of the social care workforce (Action 8, Annex A).</p>
15	NHS Improvement to implement and then monitor adherence to Trust Learning Disability standards.	NHS Improvement	September 2018	Complete – NHS Improvement published its learning disability standards in 2018.
16	The Department of Health and Social Care to commission Skills for Care to undertake a comprehensive skills and training audit of the social	Department of Health and Social Care/ Skills for Care	March 2019	Ongoing – detailed in this report.

Action	Description	Owner	By when?	Status
	care workforce based on the learning disability core skills framework.			
17	Care Quality Commission to monitor uptake of mandatory training (see action point 10) through regulatory and inspection processes; and update the Department of Health and Social Care on progress.	Care Quality Commission	From introduction of mandatory training.	Ongoing. CQC will work with the Department of Health and Social Care to agree with them how CQC's regulatory approaches could be utilised to ensure that providers are requiring staff to have received mandatory training and are meeting the requirements of the learning disability standards.
18	NHS England to publish Right Care pathways for dysphagia, epilepsy, sepsis and constipation.	NHS England	March 2019	The Diabetes pathway has been published. Sepsis: RightCare Scenario: Sepsis. NHS England has published resources on constipation.
19	NHS England to report annually to the Department of Health and Social Care on progress made on the learning into action workstream regarding work on pneumonia, sepsis, constipation early warning scores and other identified themes that require action.	NHS England	March 2019	Complete – detailed in the Action from Learning report 2019. 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 in due course.

Action	Description	Owner	By when?	Status
20	Public Health England to improve uptake of the flu vaccine for people with a learning disability.	Public Health England/ NHS England	March 2019	NHS England has delivered a flu campaign aimed at people with a learning disability as part of wider flu campaign in Winter 2019/20.
21	The Department of Health and Social Care to update on progress regarding the National Mental Capacity Forum.	Department of Health and Social Care	2019	Complete - detailed in this report.
22	NHS England to distribute additional best practice guidance on Mental Capacity Act (MCA), learning disabilities and urgent care situations.	NHS England	November 2019	Ongoing.
23	The Care Quality Commission to further develop inspection expertise to assess the quality of MCA application and practice.	Care Quality Commission	October 2019	Action is ongoing. CQC ran a special internal series of learning events for inspectors and other staff in a number of Mental Capacity Act specific topics throughout May 2019. External speakers included local authority MCA leads and law/human rights subject matter experts. Training materials from the events continue to be available to staff who also from October 2019 have had access to Health Education England's recently launched MCA e-learning.

Action	Description	Owner	By when?	Status
24	Health Education England to publish e-learning on Learning from Deaths.	Health Education England	August 2018	<p>The e-learning package 'Learning from Deaths', developed by Health Education England and Skills for Health, provides uniformity and relates directly to the good working approaches included in the guide produced by the Care Quality Commission.</p> <p>The aim of the e-learning is to encourage a learning and quality improvement culture within the health and care sectors. It helps organisations remove barriers and enable a change in culture whereby all learning opportunities are taken. This in turn will result in improvements in care.</p>

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Mental Health, Dementia and Disabilities Directorate/Dementia and Disabilities Branch

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