Department of Health & Social Care

NHS England

The Government response to the Learning Disabilities Mortality Review (LeDeR) Programme Second Annual Report

September 2018

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Foreword

Every death represents a deep personal loss to someone.

How much more tragic is that loss when the person dies years earlier than expected, or as a result of something which might under different circumstances have been prevented? For people with a learning disability this is an all too common occurrence.

The evidence of sustained and profound health inequalities for people with a learning disability is compelling and cannot be ignored. Across all public services – indeed across society – we can and must do better. We know that too many people with a learning disability die prematurely. The deaths reviewed by the Learning Disabilities Mortality Review (LeDeR) show that compared with the general population, the median age of death is 23 years younger for men and 29 years younger for women and often for entirely avoidable reasons. Some factors may not have been avoidable and mistakes can be made, but we must learn from these occurrences quickly, and translate that learning into effective remedial action which prevents any repetition.

As the first ever review on a national scale of learning disability mortality, the LeDeR programme gives us the opportunity to make a real difference, locally and nationally, to put in place new measures to effectively address the profound and persistent health inequalities faced by people with a learning disability.

The second annual report of LeDeR, published in May, was an important reminder that there is still much to do. We therefore accept all of the report's recommendations. The Department of Health and Social Care and NHS England have been working with NHS Improvement, NHS Digital, Health Education England, Public Health England and the Care Quality Commission to develop considered responses to, and implement, the annual report's recommendations.

Most importantly we want health and care staff to have the right training to support people with a learning disability, their families and carers; to ensure that perceptions of learning disability do not prevent a robust assessment of physical health, and that staff can make personalised, reasonable adjustments to care. We are taking steps to make this happen.

We know that families and the many people working in health and care settings want the best outcomes for people with a learning disability. We are determined that this review process, and the responses to the recommendations that result from it, should

enable us to make sustained and lasting change to the lives and wellbeing of people with a learning disability, their families and carers.

Caroline Dinenage
Minister of State for Care
Department of Health and Social Care

Ray James CBE
National Learning Disability Director,
NHS England

Introduction and context

1. The Learning Disabilities Mortality Review (LeDeR) programme was established to support local areas across England to review the deaths of people with a learning disability, to draw out learning from those deaths and to put that learning into practice. We want all local areas to improve the quality of the health and social care services provided to people with a learning disability, and to address the persistent health inequalities they face. LeDeR is the first national programme in the world set up to systematically review the deaths of all people with a learning disability aged four years and above which are notified to it and to embed mortality review processes across the country. Following the publication of the report of the Confidential Inquiry into Premature Deaths of People with a Learning Disability (CIPOLD)[1] in 2013, the Norah Fry Centre for Disability Studies at the University of Bristol, which led CIPOLD, was commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England to establish the LeDeR programme with the intention of ensuring that all local areas in England have their own mortality review programmes in place by 2017. Work on the LeDeR programme began in June 2015, initially for a three year period.

2. This programme is taking place within the context of a sharper focus on learning from all deaths. The Care Quality Commission's (CQC) report of December 2016, *Learning candour and accountability*,[2] recommended that Trusts needed to prioritise learning from deaths of people with a learning disability. A National Learning from Deaths Programme Board was established to oversee progress made against this recommendation and the other recommendations made by the CQC as part of a Learning from Deaths Programme. A key objective of this programme is to ensure greater scrutiny of care for people with a learning disability and mental health needs, in all healthcare settings. The key recommendation was addressed when the National Quality Board published National Guidance on Learning from Deaths[3] in 2017. This guidance emphasises the importance of learning from reviews of the care provided to people who subsequently die, and establishes that all in-patient, out-patient and community patient deaths of people with a learning disability should be reviewed.

3. In June 2018, the Government published a response to a consultation on the introduction of medical examiners and the reforms of death certification in England and Wales.[4] This sets out the intention to introduce a system of medical examiners in England. Medical examiners will reinforce the work of the Learning from Deaths programme and enhance patient safety by scrutinising every death that is not considered by a coroner, improving the accuracy of death certification and strengthening arrangements for the bereaved to raise any concerns.

4. The second annual report[5] of the LeDeR programme, covering the period July 2016 to November 2017, was published by the University of Bristol in May 2018. It provided nine key recommendations based on the evidence from the 103 reviews completed within the reporting period. By November 2017 the programme was not fully operational in all Clinical Commissioning Group (CCG) areas, although all but two of the 39 steering

groups had been established. Since publication of the report, all steering groups have now been established. As of August 2018, 476 reviews have been completed with a further 261 completed reviews in the Quality Assurance process, a total of 737 completed reviews (compared to 103 reviews completed in the period covered by the second annual report).

5. Acknowledging that there are reviews still to be completed, NHS England has allocated an additional £1.4 million to support local CCGs delivering the programme, to ensure that reviews of deaths notified to the programme are completed in a timely manner. Supporting learning disability premature mortality reviews features in the NHS 2018-19 planning guidance, *Refreshing NHS Plans for 2018/19*[6] published in February 2018. This guidance directs CCGs to report on supporting reviews of deaths of patients with a learning disability, as described in the *National Guidance on Learning from Deaths.* The 2017/19 NHS Standard Contract has also been altered to instruct Trusts to comply with the *National Guidance,* which clearly directs the review of all learning disability deaths.

6. The issues and causes of death identified within the second annual report reflect the many challenges that people with a learning disability face. There is much work already underway to improve access to healthcare and to address inequality for people with a learning disability. Through the development of new tools to support practitioners, and new resources to develop skills and awareness, we are creating a culture within health and social care of improved access, and vigilant and proactive support for people with a learning disability. But there is clearly more to do.

7. The following sections set out our formal response to each of the national recommendations of the LeDeR programme's second annual report. The LeDeR programme does not review deaths of people with autism if they do not also have a learning disability; however, many of the actions in this response will also benefit people with autism.

8. Although the LeDeR programme was commissioned on behalf of NHS England, the recommendations are aimed at the wider health and care system as a whole. This response is therefore produced jointly by the Department of Health and Social Care (DHSC) and NHS England with crucial support from arm's length bodies, including Health Education England, NHS Digital, the CQC and NHS Improvement.

Responding to the recommendations

Recommendation one

Strengthen collaboration and information sharing, and effective communication, between different care providers or agencies.

9. Promoting effective communication is at the heart of our improvement work to reduce premature mortality. There are a number of initiatives currently in place or being developed that will strengthen communication and information sharing between health and social care organisations. A number of the initiatives that are referenced in this response (for example, Annual Health Checks, Health Action Plans, the Named Social Worker model and the NHS Digital projects), all act to improve inter-professional communication across agencies, to support the health and wellbeing of a person with a learning disability.

10. LeDeR reviews increase local awareness and communication of learning disability issues. It is central to the LeDeR review methodology that learning and resulting recommendations are shared locally across all relevant health and social care organisations. Local LeDeR Delivery Steering Groups across CCG areas comprise a range of agencies and stakeholders. As the programme is fully implemented over the coming year, this sharing of information and learning across these organisations will become standard practice. All local steering groups are encouraged to promote interagency communication and collaboration in their work and the local action plans that are produced following reviews. NHS England, in partnership with the LeDeR programme office at the University of Bristol, are strengthening the reporting on local actions which should follow reviews. This reporting will be used to further support the promotion of improved interagency communication.

11. All organisations which provide NHS care and those providing publicly-funded adult social care are legally required to follow the Accessible Information Standard.[7] The Standard requires a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss. It helps to ensure people get the information they need to stay healthy, in a format they can understand, for example by providing information in an easy-read format. DHSC is working with the CQC and NHS Improvement to ensure this is being implemented fully by NHS Trusts.

12. The recently published (June 2018) NHS Improvement Learning disability standards[8] specify that NHS Trusts measure the services they provide against clearly defined standards, to identify improvements. Information about each trust is to be collected centrally, which will enhance both the quality of information being collected and

strengthen communication between different NHS Trusts, NHS Improvement and other arm's-length bodies.

13. Supporting the Accessible Information Standard is work led by DHSC and NHS England to deliver the Digital Transformation Portfolio as highlighted in the Five Year Forward View.[9] The aim of this work is to further strengthen information-sharing and collaborative working to improve personalised care for people by ensuring everyone has a secure and accessible electronic record containing all the important healthcare information.

Actions in response to recommendation one.

Action	Description	Owner	By when?
1	Report on accessible information in learning disability services in NHS Trusts.	Care Quality Commission/ NHS Improvement	October 2019
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

Recommendation two

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.

14. NHS England is working with DHSC to deliver the Digital Transformation Portfolio ambition as described in our response to Recommendation one above.

15. A Summary Care Record (SCR) is a way of telling health and care staff important information about a person. These records should include information about a person's medication and any allergies or adverse reactions to medicines that they may have. SCRs can be accessed by authorised clinicians treating patients away from their GP practice. Over 98% of GP practices in England use the SCR which contains key information from patients' GP records.

16. People can choose to have additional information shared through their SCR by providing explicit consent to their GP practice to do so. We want to ensure that this capability is used well to support people with a learning disability.

17. A doctor might ask a person with a learning disability if they can add some relevant information to the SCR. This means if a person needs treatment by other services, such as urgent or emergency care, the provider would know to provide more accessible support. This approach is promoted through the Annual Health Check Programme and links to Health Action Plans, as detailed in Recommendation three below.

18. NHS England and NHS Digital are further strengthening accessibility through a reasonable adjustment 'flagging' project, which will provide a flag on the SCR to indicate the support needs and associated reasonable adjustments that an individual requires, and consideration can be given to this prior to any appointments. Further development and testing will ensure this is implemented and embedded successfully.

19. In addition to this, NHS England is leading on establishing Local Health and Care Record Exemplars (LHCREs) as part of a wider initiative using technology to integrate services. Working at a regional level and across care settings, healthcare staff will have a comprehensive view of an individual's records based on information from the full range of services they access. An initial set of five LHCREs has been identified (Greater Manchester, Wessex, One London, Yorkshire and the Humber, Thames Valley and Surrey), and will deliver these capabilities over the next two years.

Actions in response to recommendation two.

Action	Description	Owner	By when?
3	Update to the Department of Health and Social Care on progress made in Flagging and SCR development work.	NHS Digital/ NHS England	November 2018
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
5	NHS England to review how 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

Recommendation three

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).

20. Good progress has already been made and actions to address and implement this recommendation are in place.

21. Health Action Plans are available to people through the Learning Disabilities Annual Health Check. These Health Action Plans can contribute to an individual's broader Person-Centred Plan which contains a section on their health needs. With an individual's consent, the National Electronic Annual Health Check Template section on information sharing between organisations,including the offer of a SCR with Additional Information, can be completed.

22. We believe that even more people should have Annual Health Checks, so we can continue to improve access to healthcare for people with a learning disability. In NHS England and NHS Improvement's joint planning guidance,[10] CCGs are asked to increase the number of people receiving an annual GP-led health check, to see year on year increases. CCGs should achieve this by both increasing the number of people with a learning disability recorded on the GP Learning Disability Register, and by improving the proportion of people on that register receiving a health check.

23. To measure progress, the CCG Improvement and Assessment Framework (CCG IAF) reports on both the proportion of people with a learning disability on the GP register receiving an annual health check and on the completeness of the GP learning disability register.

24. As outlined above, NHS England is working closely with NHS Digital to promote the benefits and uptake of integrated SCRs with Additional Information. This information is accessible and visible to any clinician in any setting with approved access to the NHS Spine information system.

25. There are a range of helpful resources[11] from Public Health England providing guidance for social care staff on how to help people with a learning disability get better access to medical services to improve their health.

Actions in response to recommendation three.

Action	Description	Owner	By when?
6	NHS England to report progress on uptake of Annual Health Checks to the Department of Health and Social Care via CCG IAF.	NHS England	Annually

Recommendation four

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.

We agree that coordinating care across and within health and care services is a crucial determinant of outcomes. We will be reviewing best practice on care coordination to identify approaches that work best for people with a learning disability with two or more long-term conditions.

26. There are a number of locally-developed approaches to providing a single named contact for a person with learning disability who can help co-ordinate care and help navigate a way through services, or provide key-working support. We want to encourage innovation in this area, identifying the aspects of this role which work best, and disseminating it widely.

27. The findings from the DHSC-funded Named Social Worker pilot demonstrate how people with a learning disability can be supported and advocated for to achieve better outcomes. We will review these findings and assess the potential for learning to be applied within broader health settings.

28. To identify the best practice on care coordination, DHSC will commission a rapid review of best practice in this area this year, to see what works well, and how this can be further disseminated and adopted more widely. We will draw on this evidence to produce guidance for the NHS on how best to coordinate care for people with a learning disability and long term health conditions in line with a care plan.

29. NHS England is investing £2 million in transformational funding, working in partnership with the Department for Education, to accelerate progress of six Transforming Care partnerships (TCPs) supporting children and young people who have a learning disability, autism or both with a mental health condition and / or behaviour that challenges. The programme is intended to support and accelerate the work of TCPs in strengthening the support given to children and young people who are most at risk of being admitted into care. We have asked the TCPs to consider using this as an opportunity to test locally developed models of care-co-ordination and key working for children and young people.

Actions in response to recommendation four.

Action	Description	Owner	By when?
7	Disseminate the evaluation of the Named Social Worker model.	Department of Health and Social Care	July 2018

8	Undertake a rapid review of best practice in care-coordination / key working for people with a learning disability, focused on health and wellbeing, to inform guidance for the NHS on care-co-ordination.	Department of Health and Social Care	March 2019

Recommendation five

Providers should clearly identify people requiring the provision of reasonable adjustments, record the adjustments that are required, and regularly audit their provision.

30. Where someone meets the definition of a disabled person in the Equality Act 2010 (the Act), public service providers are required to make reasonable adjustments to any elements which place a disabled person at a substantial disadvantage compared to non-disabled people. In addition, the Health and Social Care Act 2012 (Section 13G) says that the NHS has a duty to have regard to reducing inequalities in access and outcomes.

31. As described in Recommendation two above, NHS England is working with NHS Digital to develop a reasonable adjustment flag to be added to the medical records of people with a learning disability. This will support care providers by sharing and clearly 'flagging' the support needs and associated reasonable adjustments an individual requires. Further development and testing will ensure this is applied successfully and ensure information is not duplicated unnecessarily.

32. The reasonable adjustment flag project is intended to support and complement existing systems, structures and tools including the Annual Health Check, individuals' personal Health Action Plans, hospital passports and SCRs. The 'flag' will alert staff to the need to make reasonable adjustments, for example providing easy read information, allowing extra time for appointments, involving carers, and using plain English and avoiding using medical jargon where possible.

33. The NHS Digital Reasonable Adjustment Flagging Project is currently at an advanced stage of development and a pilot will begin this autumn. Full national rollout is planned for 2020. This work is being co-produced with people with lived experience. The work will be supported by detailed guidance on implementation that will be published in 2019. As described above, consideration is also being given to how this flag and the associated information can be added to the integrated records established by LHCREs and vice-versa to ensure that consistent information is being used.

34. The CQC and NHS Improvement will consider with health and social care providers how they are able to monitor and ensure providers clearly identify people requiring the provision of reasonable adjustments, record the adjustments that are required, and regularly audit their provision. The current CQC inspection methodology, through key

lines of enquiry and characteristics of ratings, assesses how well providers address reasonable adjustment needs for people using services.

Actions in response to recommendation five.

Action	Description	Owner	By when?
4 (repeated)	Once testing is complete, NHS England and NHS Digital to develop clear guidance on how the 'flagging system' will support clinical practice. NHS England will continue to support the use of additional information in the SCR through the Annual Health Check Programme.	NHS England/ NHS Digital	March 2020
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	Feb 2019
10	Implement NHS Digital Reasonable Adjustment Project roll-out and as part of this align with the LHCREs to ensure the same information is being used in both.	NHS Digital/ NHS England	2020

Recommendation six

Mandatory learning disability awareness training should be provided to all staff, delivered in conjunction with people with learning disabilities and their families.

We agree that health and care staff should have access to learning disability awareness training. We will consult by the end of March 2019 on options for delivering this to staff.

35. We are committed to basic training in, and awareness of, learning disability for health and care staff. Furthermore, we accept the advantage of delivering such training in conjunction with people with lived experience. We strongly recommend that all employers involve people with lived experience in the development and deployment of training.

36. All employers already have a clear responsibility set out in legislation to make sure that staff are competent to perform their role. The *Health and Social Care Act 2008 (Regulated Activities) Regulations 2014,* require that any person employed by a regulated service must 'receive the support, training, professional development, supervision and appraisal as is necessary to enable them to carry out the duties they are employed to perform.' In practice, for people and services which care for and treat people

with a learning disability, the nature of the necessary skills and competencies are set out in the *Learning Disability Core Skills Education and Training Framework* (2016).[12]

37. This Framework describes the core skills and knowledge required in three 'tiers':

- Tier 1 - for roles that require general awareness of learning disabilities;
- Tier 2 - for roles that will have some regular contact with people (children, young people and adults) with a learning disability, and;
- Tier 3 - for those staff directly providing care and support for people (children, young people and adults) with a learning disability.

38. While in principle employers are required to ensure that their staff have the core skills and knowledge to care for, treat and support people with a learning disability, the LeDeR report and campaigns such as Mencap's Treat me well, demonstrate that in practice this isn't always the case. We will take immediate steps (detailed below) to remind employers of their responsibilities to raise the profile of the Framework, stimulate provision of training generally and to measure uptake. But persistent inequalities have endured for some of our most vulnerable citizens for too long. **For this reason, we will consult on options for delivering mandatory learning disability training for all relevant staff**. Consultation will take place with people with lived experience, the wider learning disability sector, NHS and social care providers and the general public to ensure that proposals are practicable and effective and to avoid any training becoming a 'box-ticking exercise'. The consultation will be completed by March 2019.

Immediate action on awareness training

39. We want to make sure that there is greater understanding and awareness of the Framework and that employers, in meeting their responsibilities to train their staff, choose training that is consistent with the Framework. DHSC and NHS England will write to professional groups and all employers to remind them of their statutory responsibilities and how they can employ the Framework to inform their learning needs analysis, appraisals and training plans.

40. We will support employers by developing a Tier 1 awareness training package which will be made available to all staff. Health Education England will work with experts by experience to develop this package. We are clear that this is a minimum and does not remove the need for employers to train staff to Tier 2 requirements where appropriate.

41. DHSC, NHS England, NHS Improvement and the CQC will work together to develop guidance on how learning disability training is considered 'essential' for all staff in line with the prevailing regulations. The CQC will then be able to assess the extent to which it has been provided in its inspections in line with the regulations. We will conduct an audit of core skills and knowledge across employers at Tier 1 within 12- 36 months.

42. Additionally, Health Education England will write to professional bodies and education providers and ask them to review standards and curricula and, where required, embed the Tier 1 Learning Disability awareness requirements in line with the core skills framework in their requirements.

43. NHS Improvement has developed a range of learning disability standards for NHS Trusts[13] that will complement developing widespread training. The standards were published in June 2018 and have been developed to ensure NHS Trusts monitor and review the care they provide to people with a learning disability, autism or both. The standards are the first of their kind nationally and will assist NHS Trusts to identify areas of improvement. In doing so, they will provide a range of benefits to the individuals, families, carers and Trust hospitals; including:

- helping to reduce the variability of patient experience across NHS Trusts;
- informing Trusts' strategic planning for how they improve their services for people with learning disabilities, autism or both;
- enabling colleagues working in the NHS to understand how quality in one part of the system can impact on another;
- improving the coordination and delivery of services to a population of individuals who are known to have significantly greater numbers of co-morbidities than the general population;
- improving care quality and patient satisfaction and productivity.

44. We will ensure that providers can only be judged to have met these standards when all their staff have the core skills and knowledge in line with Tier 1 of the the Learning Disability Core Skills Education and Training Framework.

Actions in response to recommendation six.

Action	Description	Owner	By when?
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
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* and reminding them of responsibilities in respect of training.	NHS England/ Department of Health and Social Care	September 2018
13	Health Education England to develop and publish a Tier 1 training offer.	Health Education England	2019

14	Health Education England to audit provision of learning disability training.	Health Education England	June 2021
15	NHS Improvement to implement and then monitor adherence to Trust learning disability standards.	NHS Improvement	September 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 care workforce based on the learning disability core skills framework.	Department of Health and Social Care / Skills for Care	March 2019
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 (subject to consultation).	Care Quality Commission	From introduction of mandatory training.

Recommendation seven

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.

45. NHS England has established a 'learning into action' group, with experts by experience, NHS Improvement, Health Education England, NHS provider organisations, NHS Resolution (formerly the NHS Litigation Authority), the Royal College of Nursing urgent care forum and learning disability hospital liaison nursing networks. The group is looking to address the main causes of mortality identified through LeDeR, as well as developing a package of best practice measures and urgent health interventions across health and social care for people with a learning disability.

46. Specific work on the early detection of symptoms of sepsis, dysphagia, pneumonia, constipation, epilepsy and the effective use of the Mental Capacity Act (MCA) in urgent care settings is already underway. NHS England are also working with the Right Care Programme to produce better pathways of care tailored to the needs of people with learning disability and have published a reasonable adjustments pathway for diabetes. NHS England will publish further pathways for dysphagia, epilepsy, sepsis and constipation over the course of the next year.

47. There is also a focus on preventative action, with work underway by Public Heath England aimed at improving uptake of the flu vaccine for people of all ages with a learning disability.

Actions in response to recommendation seven.

Action	Description	Owner	By when?
18	NHS England to publish Right Care pathways for dysphagia, epilepsy, sepsis and constipation.	NHS England	March 2019
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
20	Public Health England to improve uptake of the flu-vaccine for people with a learning disability.	Public Heath England/ NHS England	March 2019

Recommendation eight

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.

48. This recommendation is being addressed via the NHS England 'learning into action' group and through promotion of this issue through ongoing education and review work related to the MCA.

49. The DHSC is working to support good local implementation of the Act through:

- creation of the National Mental Capacity Forum, chaired by Baroness Finlay to support strong local implementation and work to identify areas which can be improved in the implementation of the MCA. Baroness Finlay, will in particular, be leading work with key organisations this year to improve training and spread good practice;
- co-chairing with the Ministry of Justice an implementation group bringing together national statutory partners, including NHS England, to align work programmes;

- strong programmes of work around dementia, learning disability and mental health, supporting and reinforcing the cultural change envisaged by the MCA of person-centred care and dignity and respect for all;

- ensuring the MCA is a key line of inquiry in the CQC inspection regime and that their findings on Deprivation of Liberty Safeguards are included in their annual State of Care report.

50. We acknowledge that more needs to be done to embed the principles of the MCA in everyday practice. Every part of the system has a role to play and the Government is showing leadership on this through the National Mental Capacity Forum.

51. The National Mental Capacity Forum's Chair's annual report for 2017,[14] published in May 2018, discussed the Forum's continuing progress in embedding the five principles of the MCA: to presume capacity; provide support; support individuals irrespective of unwise decisions; consider the best interests of an individual; and consider the less-restrictive option. The Forum is working to raise awareness of the MCA's wide application and is developing tools to promote the Act and its workings identifying and driving local actions to improve awareness.

52. The NHS England-led learning into action group is writing specific learning disability focused MCA guidance for urgent health care situations. This work is directly informed from learning achieved through LeDeR premature mortality reviews.

53. CQC inspections should always assess the quality of practice with respect to the application of the MCA. The CQC will work with NHS England, NHS Improvement and other bodies to consider further work in relation to MCA and inspections.

Actions in response to recommendation eight.

Action	Description	Owner	By when?
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
22	NHS England to distribute additional best practice guidance on the MCA, learning disabilities and urgent care situations.	NHS England	November 2018
23	The Care Quality Commission to further develop inspection expertise to assess the quality of MCA application and practice.	Care Quality Commission	October 2019

Recommendation nine

A strategic approach be taken nationally for 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.

54. Health Education England has carried out a scoping exercise to understand what training for reviews and investigations is currently available in the NHS. Health Education England, supported by the national Learning from Deaths programme board partners, is also developing e-Learning for clinicians and reviewers which will be published shortly. This incorporates the Board-level guidance and complements the guidance for families and carers. Topics for the e-Learning package will include:

- culture and learning from deaths;
- engaging with families and carers;
- care record reviews and investigations;
- actions and improvements;
- Trust boards and the role of non-executive directors.

55. The Healthcare Safety Investigations Branch (HSIB) has been established to conduct safety investigations in the NHS and will be an exemplar for local investigations. HSIB has been in operation since April 2017 and is continually assessing its methodology as it carries out investigations, including how this approach can then be applied locally. The expectation is that eventually HSIB will play an important role in considering its approach to supporting investigation training for reviewers in line with the CQC recommendation in *Learning candour and accountability*,[15] potentially through bespoke accredited training for investigators, face-to-face visits or development of national standards.

Actions in response to recommendation nine.

Action	Description	Owner	By when?
24	Health Education England to publish e-Learning on learning from deaths.	Health Education England	August 2018

How actions will be monitored

56. DHSC and NHS England will establish a LeDeR oversight group, including people with lived experience and family representatives. This group will meet regularly to monitor cross- system progress against recommendations and agreed actions, and can link as necessary with the LeDeR independent advisory group, and provide advice to Ministers and policy leads.

Summary of actions in response to recommendations

Action	Description	Owner	By when?
1	Report on accessible information in learning disability services in NHS Trusts.	Care Quality Commission/ NHS Improvement	October 2019
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
3	Update to the Department of Health and Social Care on progress made in Flagging and SCR development work.	NHS Digital/ NHS England	November 2018
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
5	NHS England to review how 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
6	NHS England to report progress on uptake of Annual Health Checks to the Department of Health and Social Care via CCG IAF.	NHS England	Annually
7	Disseminate the evaluation of the Named Social Worker model.	Department of Health and Social Care	July 2018
8	Undertake a rapid review of best practice in care-coordination / 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

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	Feb 2019
10	Implement NHS Digital Reasonable Adjustment Project roll-out and as part of this, align with the LHCREs to ensure the same information is being used in both.	NHS Digital/ NHS England	2020
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
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* and reminding them of responsibilities in respect of training.	NHS England/ Department of Health and Social Care	September 2018
13	Health Education England to develop and publish a Tier 1 training offer.	Health Education England	2019
14	Health Education England to audit provision of learning disability training.	Health Education England	June 2021
15	NHS Improvement to implement and then monitor adherence to Trust Learning Disability standards.	NHS Improvement	September 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 care workforce based on the learning disability core skills framework.	Department of Health and Social Care/ Skills for Care	March 2019
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.

18	NHS England to publish Right Care pathways for dysphagia, epilepsy, sepsis and constipation.	NHS England	March 2019
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
20	Public Health England to improve uptake of the flu-vaccine for people with a learning disability.	Public Heath England/ NHS England	March 2019
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
22	NHS England to distribute additional best practice guidance on MCA, learning disabilities and urgent care situations.	NHS England	November 2019
23	The Care Quality Commission to further develop inspection expertise to assess the quality of MCA application and practice.	Care Quality Commission	October 2019
24	Health Education England to publish e-Learning on learning from deaths.	Health Education England	August 2018

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