

Learning Disability Mortality Review (LeDeR) Programme: Action from Learning

NHS England and NHS Improvement



Publishing Approval Reference: 000373

This document is available as an easy-read and can be provided in alternative formats upon request.

This document uses images from Photosymbols®.

May 2019

Contents

Foreword from a bereaved relative	4
Foreword from a person with a learning disability	5
Foreword from NHS England and NHS Improvement	5
Introduction	7
NHS England's and NHS Improvement's response to the LeDeR annual report 2018	7
NHS England's and NHS Improvement's action plan	8
Making a difference locally	8
Making a difference nationally	8
Sepsis and the deteriorating patient work stream	9
Constipation	11
Dysphagia	11
Cancer	12
Mental Health Capacity Act	12
Valuing the input of bereaved families	13
Communicating our work	13
Establishing an online network	14
Conclusion	14
Summary and next steps	14
ANNEX 1: NHS England and NHS Improvement actions from the Government's response to the second annual LeDeR report	16
ANNEX 2: LeDeR planning guidance deliverables for CCGs	20
ANNEX 3: NHS England and NHS Improvement LeDeR Action Plan 2019/2020	21
ANNEX 4: Local service improvement examples	28
Service improvements in acute hospitals	28
Service improvements in community learning disability teams	29
Service improvements in primary care	30
Service improvements for family carers and paid carers	32
Other service improvements	33

Foreword from a bereaved relative

When my happy, healthy and much-loved brother Richard died suddenly and unexpectedly in 2012 of constipation, I was devastated. Not only had I lost my wonderful and mischievous big brother, my eyes had been opened to the extent of inequalities faced by people with a learning disability.

Richard was 33 when he died and his death raised serious alarm bells for me and my family. It was clear that improvements were needed across health and social care services, to make sure that no other people with a learning disability could die of such a preventable and treatable condition. We were left feeling very worried about other people with a learning disability, especially people without families to speak up for them. We were amazed by how hard we as a family, and many others, had to fight to make sure that services learnt from the deaths of people with a learning disability.

When Richard died, I could only dream of a time when mortality reviews would be routine for all deaths and family involvement would be viewed as paramount. Our experiences left me unable to imagine this happening in my lifetime and yet the LeDeR programme has introduced clear expectations on health and social care services and public bodies when anyone with a learning disability dies.

I still miss Richard terribly but am heartened to see how far things have come since he died. Indeed, the LeDeR programme requires that all deaths are reviewed, that families are involved throughout reviews and that service improvements are made to improve care for other people.

There is undoubtedly still a long way to go. Every single untimely death is absolutely a death too many. I am hopeful though that the tide is turning and that the changes that so many of us passionately fight for, will be realised in my lifetime. I have had the privilege of meeting many other bereaved families, people with a learning disability, their families, carers, and professionals who share a commitment to making sure that health inequalities are addressed and that premature mortality is no longer seen as an inevitability.

Families like mine, who live with the pain and loss of our missing loved ones every day, will not be reassured until more action has been taken, more improvements have been made and people with a learning disability and their families routinely report more positive experiences of health and social care.

Families and people with a learning disability will, quite rightly, remain concerned until the backlog of unreviewed deaths is addressed and LeDeR reviews are routinely completed in a timely way. We also need reassurance that the requirements introduced by LeDeR to meaningfully involve bereaved families throughout reviews are consistently met.

NHS England and NHS Improvement are committed to making sure that more mortality reviews are carried out and that the concerns of bereaved families, people with a learning disability, their families and carers, and indeed many professionals, are allayed.



Richard and Emily

Dr Emily Handley-Cole is a learning disabilities clinical psychologist, currently employed by NHS England and NHS Improvement as a national premature mortality governance and development lead for the LeDeR programme.

Foreword from a person with a learning disability

I would like to say thank you to everyone who has been involved in the LeDeR programme. This is very important work which should save the lives of people with a learning disability.

This report tells us about the 'action from learning' work across England. It tells us about changes happening to make services better in different parts of the country and changes that will make services better across the country.

It is not fair that people with a learning disability die younger than other people. I am very pleased to be the expert by experience lead, working on NHS England and NHS Improvement's 'learning into action' work as part of the LeDeR programme.

Listening to and working with people with a learning disability and our families will help make sure that services meet our needs. This should help to make sure that me and my friends have the chance to live long and healthy lives like everyone else.



Aaron Oxford

Learning Disability Network Manager,
NHS England and NHS Improvement

Foreword from NHS England and NHS Improvement

The Learning Disability Mortality Review (LeDeR) programme was commissioned to improve the standard and quality of care for people with a learning disability. The third annual report, published in May 2019, provides a welcome update on the learning emerging from this vital work. This NHS England and NHS Improvement report will outline some of the extensive activity that is taking place locally and nationally in response to the learning from LeDeR reviews.

It is of great concern that the latest LeDeR report cites deaths reviewed where there were concerns about the quality of care, and an average age of death that is 23 years younger than the general population for men with a learning disability and 27 years younger for women. The LeDeR programme provides a framework for making sure that local service improvements are being made in response to learning from deaths.

It is heartening to hear that many LeDeR reviews describe people living good lives with high quality, person-centred care and support, being treated with love and respect, their life and contributions valued by people around them. Many reviews describe a thoughtful approach to end of life care, with the needs and wishes of the person and their family at the heart of decisions.

Proactive lifelong healthcare and timely treatment all make a difference in keeping people healthy and, once people are nearing the end of life, bucket lists, involvement in funeral planning, preparing housemates and fitting goodbyes have all stood out in LeDeR reviews as supporting people to have the type of death we may all aspire to.

Very often the input of a few people who show compassion, take responsibility, demonstrate

leadership and don't accept anything less than they might expect for themselves is what underpins high quality care. Learning from these situations must inform service improvements so that this becomes the standard for people with a learning disability.

The NHS Long Term Plan makes a commitment to reducing the premature mortality of people with a learning disability. As part of this, NHS England and NHS Improvement will provide funding to Clinical Commissioning Groups (CCGs) to support them to complete their outstanding reviews. There will also be investment to secure the long-term future of the LeDeR programme so that the wealth of learning it provides continues to be translated into action.

There must be universal recognition amongst all health and social care staff of the need to prioritise improvements in the quality of services, so that people with a learning disability are supported to live longer, healthier lives.

This year's report is based on findings from over 1,000 reviews; a further 650 reviews have since been completed. This may well be the most significant amount of evidence ever compiled about the deaths of people with a learning disability at an individual level. The findings are informing a growing body of vital work to improve services, both locally and nationally.

The next 12 months will see £5 million further investment to make sure that reviews are completed within six months of notification and, importantly, the inclusion of dedicated work to drive improvements for people with a learning disability across major national mainstream health programmes – including cancer, respiratory disease, primary care networks and more. There will also be increasing transparency, with local reports to NHS public board meetings and greater detail published at a national level about each area's performance in completing reviews.

We know there is much more to do and The NHS Long Term Plan reinforces the commitment to and importance of this work. Our thanks go to colleagues, to the University of Bristol team, to people with a learning disability and especially to the bereaved families who have been willing to share their experiences for the benefit of others. Without their courage and insight much of this progress would not have been possible.



Ray James, CBE

National Learning Disability Director,
NHS England and NHS Improvement



Dr Jean O'Hara

National Clinical Director for Learning Disabilities,
NHS England and NHS Improvement

Introduction

The Learning Disabilities Mortality Review (LeDeR) programme was established in May 2015 to support local areas across England to review the deaths of people with a learning disability, to learn from those deaths and to put that learning into practice.

CCGs are expected to work with their local partners including people with a learning disability, families and carers, local authorities and NHS trusts. CCGs have a responsibility 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 people often face.

This is the first report on work to translate learning into action in relation to the Learning Disability Mortality Review (LeDeR) programme carried out between spring 2018 and spring 2019. This work includes the development of the ways in which services need to change based on learning from LeDeR reviews and the sharing of that work so that local areas are able to put those changes into action.

The LeDeR programme requires CCGs across England to review all deaths of people with a learning disability aged four and over, and to improve services based on what those reviews show. CCGs must work with local health and social care providers to develop and put those local action plans into place.

This report provides examples of the local changes that have been made to services so far and highlights the extensive work which is happening nationally in response to common themes raised through LeDeR reviews across the country.

The report completes NHS England's action from the government response to the second annual LeDeR report published, in September 2018, to report annually on progress resulting from LeDeR reviews. An update on the other actions relating to NHS England and NHS Improvement is provided in Annex 1.

NHS England's and NHS Improvement's response to the LeDeR annual report 2018 (published May 2019)

CCGs, working with their local authority and NHS partners, have made significant progress towards completing LeDeR reviews in a timely way but there is still a long way to go. At the time of writing this report, 32% of reviews have been completed, a further 4% are in the final stages of sign-off and 31% are in progress. Some CCGs have completed more than 70% of reviews; however, this is variable across England and some CCGs have significantly lower completion rates.

An additional £5 million will be invested by NHS England and NHS Improvement in 2019/2020 to address the backlog of unreviewed cases and increase the pace with which reviews are allocated and completed. The money will be invested in developing a dedicated workforce to undertake reviews and develop systems and processes to embed mortality review and quality improvement activity across the health and social care system.

NHS England and NHS Improvement are committed to improving transparency and making sure that the deaths of people with a learning disability are reviewed in a timely way, to inform service improvements and honour the commitment made to bereaved families, that all deaths will be reviewed. To demonstrate this, the NHS operational planning and contracting guidance for 2019/2020 sets out clear requirements of CCGs in relation to the LeDeR programme (see Annex 2).

CCGs are now expected to publish local LeDeR annual reports which describe their progress on completing reviews and the service improvements they have made because of what has been learnt. Moving forward, data on the progress of review completion will also be published regularly on the NHS England and NHS Improvement website.

NHS England's and NHS Improvement's action plan

NHS England and NHS Improvement have developed an action plan in response to the LeDeR 2018 report. Its purpose is to ensure that prompt and effective action is taken to address the learning identified about factors that can contribute to premature mortality. A commitment has been made by a number of national programmes across NHS England and NHS improvement to focus on reducing healthcare inequalities for people with a learning disability, in relation to cancer, constipation, respiratory disease, sepsis, pharmacy, annual health checks, improvement standards and do not attempt cardiopulmonary resuscitation orders (DNACPRs). The action plan is included in Annex 3.

Making a difference locally

One of the LeDeR programme's primary aims is to make sure that local learning from completed LeDeR reviews leads to prompt service improvements in local areas. Learning from local mortality reviews have already led to significant service changes across England to support people with a learning disability to live longer, healthier lives. It is not possible to provide a list of every service improvement across the country as there have been so many. However, some examples are described in Annex 4. This list should be used by health and care services across England to inform quality improvement, so that changes are put in place proactively based on national learning, as well as in response to learning from locally reviewed deaths.

Making a difference nationally

A learning into action collaborative was set up by the NHS England and NHS Improvement learning disability programme to better co-ordinate national responses to premature mortality review learning. It brings together arms-length bodies, partners, NHS provider trusts, independent health and care providers, clinicians, charities and people with a learning disability and their families.

The work of the collaborative has been guided by the themes reported in the 2018 University of Bristol LeDeR report. This report stated that, of the LeDeR cases reviewed to date, the most common causes of death were pneumonia, sepsis and aspiration pneumonia. Mortality reviews also indicated that issues such as constipation, the failure to recognise physical deterioration, and the application of the Mental Capacity Act applied to physical health issues were also significant factors in avoidable deaths.

The collaborative work plan for 2018/19 focussed exclusively on these areas. As new issues are identified from future LeDeR annual reports, they will also be explored and addressed.

There are a wealth of localised good practice and innovative approaches being delivered across the country to prevent premature mortality. However, it was felt that the development of good practice could be better co-ordinated, promoted and shared nationally.

The learning into action collaborative was formed to improve this situation, and to stimulate the development of new solutions focusing specifically on the needs of people with a learning disability. Its aim is to identify issues and address them through best practice measures and urgent health interventions in health and social care. The collaborative also connects with existing national programmes that endeavour to reduce avoidable deaths, such as GP Annual Health Checks, STOMP, the NHS digital flagging project, 'Ask, Listen, Do', the cross-system sepsis programme board and the national cancer screening programme review.

Despite significant progress with LeDeR, there is still much to be done to help people with a learning disability to lead longer, happier, healthier lives. The Long Term Plan reinforces the commitment of NHS England and NHS Improvement to ensuring that this happens.

Learning into action was designed to share best practice across all health professionals. However, there is a well-recognised challenge: the majority of learning disability health improvement work is communicated predominantly from within the learning disability professional sector, whilst data from the confidential enquiry into premature deaths of people with a learning disability (2013) and completed LeDeR reviews, shows that people often experience health inequalities in other settings, such as accident and emergency departments and outpatient clinics.

It is therefore vital that this work is shared across all services, if changes are to be made that will save people's lives. Membership of this group is therefore much wider than with existing practice development groups, and currently includes:

- Family carers
- Bereaved family carers
- People with a learning disability
- NHS England and NHS Improvement (including the Learning Disability Programme, Clinical Policy Unit, and Communications team)
- NHS Resolution
- Royal College of Nursing
- University of Bristol LeDeR programme team
- West of England Academic Health Science Network
- NHS provider trusts

The learning into action collaborative comprises of a number of working groups, focused on improving care in relation to specific illnesses and areas of practice. Each group has benefited from input from experts by experience, specialist professionals and charities to make sure that the focus and outputs are effective in improving care and saving lives.

Sepsis and the deteriorating patient work stream

The LeDeR annual report published in May 2018 highlighted sepsis as a key contributor to premature mortality, with 11% of deaths being recorded as sepsis related. It recommended a national focus on sepsis for people with a learning disability, to raise awareness of prevention, early identification and treatment.

A national working group has been formed to focus on improved identification of acute deterioration, including sepsis. Its work is led by NHS England and NHS Improvement's Clinical Policy Unit and the Learning Disability Programme, and its membership includes stakeholders from across the health and care system. It reports to the national cross-system sepsis board, which was established to drive quality improvement in the prompt identification and treatment of sepsis.

Work is underway to improve the sharing of information on people with a learning disability, across health and care settings. The West of England's Academic Health Science Network is trialling the use of national early warning scores (NEWS2) in the community, to support earlier identification of deterioration and access to treatment, through improved communication between carers and healthcare staff and community and acute settings. NEWS2 was developed to standardise and improve the detection and response to clinical deterioration in patients with acute illness. Across England, there are pilots in all regions of tools to support improved recognition of deterioration in the community. Early feedback shows that these tools successfully support increased engagement of carers around physical healthcare monitoring and improved, urgent communication with healthcare professionals.

The national working group has conducted a review of the existing resources available for professionals and carers, to support the identification of deterioration (including sepsis) amongst people with a learning disability. Members of the group, including the UK Sepsis Trust, have agreed to promote good practice resources to maximise their reach and impact. Sepsis nurses from the East and North Hertfordshire NHS Trust have worked with Hertfordshire County Council health liaison team and a performing arts self-advocacy group, the Purple All Stars, to develop easy-read information on sepsis. <https://www.hertfordshire.gov.uk/media-library/documents/adult-social-services/learning-difficulties-and-dementia/sepsis/what-is-sepsis-easy-read.pdf>

The Purple All Stars have also developed a sepsis song to raise awareness and improve vigilance to the signs of sepsis amongst people with a learning disability. A supporting video has been developed so that the song and its powerful message can be shared widely. <https://www.youtube.com/watch?v=FZq5sYulOB8&feature=youtu.be>



The Purple All Stars performing the 'sepsis song'

NHS England and NHS Improvement have also worked with the lead sepsis nurse and lead learning disability nurse at Sherwood Forest Hospitals NHS Foundation Trust to develop a training film. It supports health and care professionals, and carers, to spot the softer signs of deterioration in people with a learning disability. The film features an actor with autism and a learning disability. <https://www.youtube.com/watch?v=CfIZRfFZj8c&feature=youtu.be>

NHS England and NHS Improvement have commissioned the self-advocacy theatre company MiXiT to develop and perform a short play 'Knowing Tom' on the identification of deterioration and sepsis. A very moving debut performance took place in March 2019. It aims to raise awareness amongst professionals, families and people with a learning disability.

These activities should raise awareness of the risk of sepsis and unrecognised ill health amongst people with a learning disability, their families and paid carers. They should support more confident and comprehensive communication with healthcare professionals about signs of illness, to ensure that concerns are taken seriously. If successful, this work should support timely diagnosis and treatment and reduce delays.



MiXiT theatre company performing 'Knowing Tom' play on the identification of deterioration and sepsis amongst people with a learning disability

Constipation

Twelve deaths where constipation was the recorded cause of death have been reported to the LeDeR programme to date. This is deeply concerning, since constipation is both preventable and amenable to treatment.

A national constipation working group has been established, to develop an enhanced understanding of the medical factors contributing to constipation deaths. It comprises representatives from a wide range of health and social care organisations, as well as a self-advocate with a learning disability and a bereaved family carer whose son died prematurely from constipation.

The group has developed tools and resources illustrating the risk that constipation can pose to people with a learning disability, and how it can be prevented, recognised and treated. These are available on the NHS England and NHS Improvement website at <https://www.england.nhs.uk/publication/constipation-learning-disability-resources/>

NHS England and NHS Improvement have also supported the development of a Books Beyond Words book, which is available at <https://booksbeyondwords.co.uk/> on constipation for people with a learning disability. It will help improve awareness and understanding of the risks of constipation, and the importance of getting help when needed.

Dysphagia

The LeDeR annual report published in May 2018, highlighted dysphagia as one of the most common long-term conditions experienced by people with a learning disability and reported that 16% of deaths reported to LeDeR are attributable to aspiration pneumonia. Some of these deaths will have resulted from dysphagia (swallowing difficulties), which is more common amongst people with a learning disability than in the general population.



A new national working group will develop and promote resources to improve dysphagia management, and to reduce preventable mortality resulting from the condition. The group is co-chaired by a person with a learning disability, and membership includes representation from NHS England, NHS Improvement, NHS provider trusts and social care.

There are plans for a national event in September 2019 in collaboration with Skills for Care, focusing on improving awareness and knowledge of dysphagia in people with a learning disability. The group will also oversee a learning disability dysphagia day to support Learning Disability Week in June 2019, as part of a communications strategy, to make sure that information on prevention, risk management and treatment reaches a wide audience.

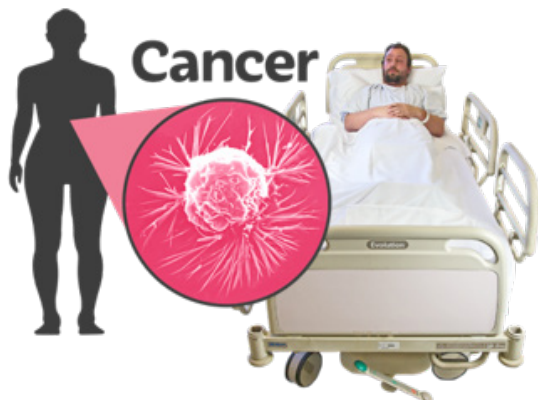


Cancer

The LeDeR annual report published in May 2019 indicated that 14% of deaths amongst people with a learning disability are attributable to cancer. This is lower than the general population, where 28% of deaths are attributable to cancer. However, the report highlighted a lack of support to access cancer screening as a potential factor in some deaths of people with a learning disability.

Work completed by the Somerset, Wiltshire, Avon and Gloucestershire (SWAG) Cancer Alliance, on behalf of the LeDeR programme, has led to a series of helpful recommendations for cancer alliances across England. Although these are aimed at reducing inequality in cancer services for people with a learning disability, they are likely to benefit all vulnerable groups.

Increasing early detection of cancers, and making them easier to treat, is at the heart of The NHS Long Term Plan. It is crucial that people with a learning disability are supported appropriately, and reasonable adjustments are made, to ensure that they can engage in cancer screening programmes.



The LeDeR programme's findings in relation to cancer deaths and issues regarding access to cancer screening have been shared with the National Review team, which is currently overseeing a major overhaul of cancer screening programmes, as part of a renewed drive to improve care and save lives. The team have agreed to include a focus on people with a learning disability within the national cancer screening review and its resulting actions. The NHS is prioritising making reasonable adjustments for screening including the roll out of easy read information.

Mental Capacity Act

The LeDeR annual report published in May 2018 highlighted the need for better understanding and application of the Mental Capacity Act (MCA). LeDeR reviewers 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.

An MCA workstream was established to explore how to support quality improvements and enhance compliance within secondary care for people with a learning disability. This work aims to:

- Raise the profile of the MCA.
- Increase healthcare workers' confidence and competence in using the MCA with people with a learning disability and their families.
- Support the development and sharing of best practice.

NHS England and NHS Improvement, acute trusts, and primary care are all represented on the working group, along with allied health professionals, designated safeguarding leads and family carers.

The working group aims to better understand the specific issues faced by people with a learning disability in relation to the MCA. It has identified examples of best practice and developed actions that can be taken locally and nationally to improve outcomes and experience for people with learning disabilities. It is also making connections with existing programmes of work, to ensure consistency of approach and desired outcomes whenever possible.

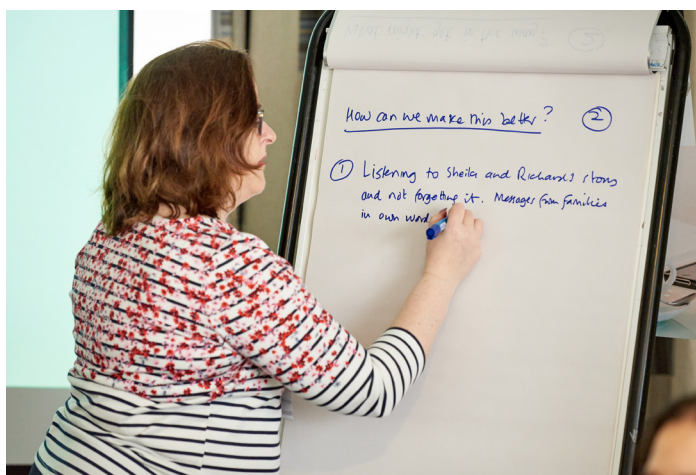


This work has resulted in the development of some initial key resources for health professionals and family carers, regarding the importance of the MCA, and how it can support patient experience and patient safety. It is hoped that these will be ready for publication in Autumn 2019.

Valuing the input of bereaved families

In 2016, the Care Quality Commission published their Learning, Candour and Accountability report, describing the experience of families and carers in the context of mortality reviews. Unfortunately, families and carers often described a poor experience of mortality reviews, which was particularly the case for families and carers of people with a learning disability.

From the outset, the involvement of families has been a core principle and value that sits at the heart of the LeDeR programme, to maximise the learning from deaths and ensure that 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.



Bereaved family carer Sheila Handley facilitating an NHS England and NHS Improvement LeDeR conference workshop with support from Mary Busk, family carer

Communicating our work

NHS England and NHS Improvement have worked with the University of Bristol LeDeR team on a series of [learning into action newsletters](http://www.bristol.ac.uk/sps/leder/news/learning-into-action-newsletters/), which communicate key messages about the learning emerging from LeDeR reviews. These are available at <http://www.bristol.ac.uk/sps/leder/news/learning-into-action-newsletters/>

Subjects have included aspiration pneumonia, sepsis, recognising deterioration, constipation and the Mental Capacity Act; case studies, examples of best practice, tools and resources, have also been included. The newsletters have been distributed to health and care professionals, people with a learning disability and family carers.

In March 2019, a national conference focusing on learning into action was held in Manchester. It was designed and delivered with a person with a learning disability, a family carer and a bereaved family carer, and focused on national and local initiatives to translate learning into action, improve healthcare and reduce premature mortality amongst people with a learning disability.

Presentations and workshops focused on service improvements relating to aspiration pneumonia, sepsis, recognising deterioration, constipation, epilepsy, the Mental Capacity Act and cancer. Focus

was also given to the importance of working in partnership with people with a learning disability, families and paid carers, to ensure high quality physical healthcare. Attendees made pledges about the actions they planned to take on return to their organisations, to contribute to improved health outcomes and reduced health inequalities.

Establishing an online network for promoting practice

It was recognised that a central searchable resource would be an invaluable aid to increasing the impact of this work.

The new learning into action network, launched in 2019, allows professionals to share practical resources and examples of innovative and best practice, join in forum discussions, and learn about solutions identified from completed mortality reviews.

This new network will support national collaboration on activity to translate the learning from completed mortality reviews into action to achieve service improvements across England for people with a learning disability.

Please email england.ldmortalitynetwork@nhs.net to join and contribute to this growing network.

Conclusion

This report summarises the growing evidence of changes being planned and implemented locally and nationally to address the premature mortality of people with a learning disability in England.

The learning emerging from the LeDeR programme is providing a focus for the development of local and national priorities for work to effect real change.

It is important to note that the LeDeR programme is just one element of the NHS England and NHS Improvement learning disability programme. Indeed, the wider programme also includes a focus on increasing the uptake of primary care annual checks, stopping over medication, reducing inpatient admissions to specialist mental health services, making sure that physical health is appropriately considered during care, (education) and treatment reviews (C(E)TRs).

NHS England and NHS Improvement are committed to addressing the premature mortality of people with a learning disability, as described in the NHS Long Term Plan.

The LeDeR programme is making progress but there is still a long way to go in making sure that reviews are completed in a timely way so that learning is translated into effective action. It is paramount that we seek evidence of universal or mainstream services implementing service improvements so that the impact of LeDeR extends beyond specialist learning disability services and higher quality care is more routinely available to people with a learning disability and their families.

Summary and next steps

There is growing recognition across the health and social care sector of the inequalities faced by people with a learning disability and their families. The LeDeR programme is opening conversations with a wide range of professionals who may have never previously considered the challenges faced by people with a learning disability and their families, either because they are perceived to be served mainly by specialist learning disability services or professionals did not have sufficient awareness of the need for reasonable adjustments.

This growing recognition is, in part, attributable to the tireless campaigning of families whose loved ones have died a potentially premature death. The LeDeR programme has introduced clear expectations relating to mortality review and NHS England and NHS Improvement are committed to ensuring that, moving forward, LeDeR reviews are completed in a timely way and lead to tangible service improvements.

This report has outlined some national and local examples of the extensive activity underway across England to improve healthcare for people with a learning disability and reduce inequalities, based on learning from LeDeR reviews. It is hoped that, through sharing these examples of service improvements, they can be emulated wherever appropriate in services across the country.

In 2019/2020 the University of Bristol will be reporting more regularly about themed learning, which is possible now that a higher number of reviews has been completed. The learning into action collaborative will continue to co-ordinate national responses to the learning emerging from LeDeR.

ANNEX 1: NHS England and NHS Improvement actions from the Government's response to the second annual LeDeR report

In September 2018, _ in response to the nine recommendations made in the University of Bristol 2016/17 LeDeR annual report. The commitments that were attributable to NHS England and NHS Improvement are set out below, including a progress update. Seven actions have been completed and seven are ongoing.

The numbers in the left-hand column correspond to the action points in the original government response.

Action	Description	Target date	Progress
1	Report on accessible information in learning disability services in NHS trusts.	October 2019	Ongoing – The learning disability improvement standards and the metrics within them, ask that trusts pay attention to their responsibility to meet the accessible information standard. Trusts are required to provide evidence of resources developed that adhere to this standard. In 2019 and each subsequent year progress on the implementation of the learning disability standards will be published.
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	March 2019	Complete – detailed in this report.
3	Update to the Department of Health and Social Care on progress made in flagging and summary care records development work	March 2020	Complete – Commitments made and published in the NHS Long Term Plan.

Action	Description	Target date	Progress
4	<p>Once testing is complete, NHS England and NHS Digital to develop clear guidance on how the flagging system will support clinical practice.</p> <p>NHS England to continue to support the use of additional information in the SCR through the annual health check programme.</p>	March 2019	<p>Ongoing - testing underway</p> <p>Guidance will be issued once testing and piloting is complete.</p>
5	NHS England to review how local health care records exemplars (LHCRES) could better integrate the approach to sharing of pertinent information between health and care providers for people with a learning disability.	March 2019	<p>Complete – Local Health Care Record Exemplars are sharing information across our health and care services to support the needs of each individual.</p> <p>This is being trialled in local transformation priorities such as Cancer in Y&H and frailty in greater Manchester.</p>
6	NHS England to report progress on uptake of annual health checks to the Department of Health and Social Care via CCG IAF.	Annually	Complete - annual health check data is published here and was assessed via the CCG Improvement and Assessment Framework.
9	Publish update to the Department of Health and Social Care on progress made in adding a reasonable adjustment flag to the SCR application.	February 2019	On-going – see update on actions 4.
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.	2020	Ongoing – testing underway, see action 4.

Action	Description	Target date	Progress
12	NHS England and the Department of Health and Social Care to write to providers and employers promoting the <i>Learning Disability Core Skills Education and Training Framework</i> and reminding them of responsibilities in respect of training.	September 2018	Complete – joint letter sent by Minister for Care, NHS England medical director and director of nursing
15	NHS Improvement to implement and then monitor adherence to trust learning disability standards.	September 2018	<p>Complete – NHS Improvement published its learning disability standards in 2018. Following the publication, NHS trusts took part in the first annual survey to measure the services they provide against a number of improvement metrics within the standards.</p> <p>The findings from the first survey are due to be published in Spring 2019. This information will then be used to identify both areas where trusts are excelling, alongside identifying where there are continued challenges.</p>
18	NHS England and NHS Improvement to publish Right Care Pathways for dysphagia, epilepsy, sepsis and constipation.	March 2019	<p>On-going – the diabetes pathway has been published:</p> <p>Publication of the pathways and guidance for dysphagia, epilepsy, sepsis and constipation is currently being reviewed to ensure pathways are integrated into service design and have the greatest impact and benefits for people with a learning disability and their families.</p>
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.	March 2019	Complete – detailed in this report.

Action	Description	Target date	Progress
20	NHS England to improve uptake of the flu vaccine for people with a learning disability.	March 2019	<p>On-going – Guidance for flu vaccinations was published in September 2018. Additional information on the risks of flu for people with a learning disability published by NHS England and NHS Improvement.</p> <p>Awaiting availability of 2018/2019 data to confirm action completion.</p> <p>NB. There will be more work to further improve reasonable adjustments for and uptake of flu vaccinations.</p>
22	NHS England to distribute additional best practice guidance on the MCA, learning disabilities and urgent care situations.	November 2018	Ongoing – NHS England and NHS Improvement are developing guidance with input from acute trusts, primary care, allied health professionals, designated safeguarding leads and family carers. Due for publication in Autumn 2019.

ANNEX 2: LeDeR planning guidance deliverables for CCGs

The NHS Operational Planning and Contracting Guidance 2019/20 includes four requirements for CCGs:

- Each CCG must be a member of a learning disabilities mortality review (LeDeR) steering group, and have a named person with lead responsibility
- There must be a robust CCG plan in place to ensure that a LeDeR review is undertaken within six months of the notification of a death in its area
- CCGs must have systems in place to analyse and address the issues and recommendations arising from completed LeDeR reviews
- An annual report, detailing the findings of local LeDeR reviews and the actions taken, must be submitted to the appropriate board/committee for all statutory partners, and shared amongst other local health and social care boards as appropriate.

ANNEX 3: NHS England and NHS Improvement LeDeR Action Plan 2019/2020

Programme	LeDeR findings	Actions completed to date	Action plan
Cancer	<p>14% of deaths amongst people with a learning disability are attributable to cancer.</p> <p>LeDeR has highlighted a lack of support to access cancer screening as a potential factor in some deaths of people with a learning disability.</p> <p>Access to cancer screening by people with a learning disability can be impeded by:</p> <ul style="list-style-type: none"> • Reduced understanding of importance of screening. • Invitation letters unlikely to be easy read. • Difficulties using appointment systems. • Lack of hoists available for people with physical impairments. • DNA recorded without consideration of whether a reasonable adjustment could support successful testing in future. • Assumptions that a person would not tolerate screening, recorded as “will be difficult” or “would not be possible”. • Anxiety, claustrophobia, sensitivity to touch (e.g. in autistic spectrum conditions). • Time pressures in screening services and a lack of reasonable adjustments. 	<p>An analysis was undertaken to understand the potentially modifiable factors contributing to deaths of people with a learning disability with cancer, reviewed through the LeDeR programme.</p> <p>NHS England and NHS Improvement have worked with the national cancer screening review team to ensure that a focus on people with a learning disability is included within the review and its resulting actions.</p>	<p>NHS England and NHS Improvement will ensure that all screening programmes that it commissions are designed to support a narrowing of health inequalities. This work will include meeting the needs of those with learning disabilities.</p> <p>NHS England and NHS Improvement will continue to work with PHE to ensure that all screening programmes are designed to support a narrowing of health inequalities and that this is reflected within provider contracts.</p> <p>NHS England and NHS Improvement Public Health Commissioning Team are continuing to work with PHE to implement the PHE Screening Inequalities Strategy.</p> <p>NHS England and NHS Improvement will develop and publish a ‘menu’ of evidence-based interventions that, if adopted locally, would ensure programmes are focused on health inequality reduction.</p> <p>NHS England and NHS Improvement cancer (and mental health) technology initiatives aim to help clinicians and improve patient experience through technology. This will be supported through use of the reasonable adjustment ‘digital flag’ accessible in the patient record or through summary care record as an alternative, to alert NHS staff to make the necessary service adjustments that improve health outcomes for people with a learning disability.</p>

Programme	LeDeR findings	Actions completed to date	Action plan
Constipation	Twelve deaths where constipation was the recorded cause of death have been reported to the LeDeR programme to date. This is deeply concerning, since constipation is both preventable and amenable to treatment.	<p>NHS England has established a national constipation working group, to develop an enhanced understanding of the medical factors contributing to constipation deaths.</p> <p>Tools and resources have been developed for professionals, people with a learning disability and carers, illustrating the risk that constipation can pose to people with a learning disability, and how it may be prevented, recognised and treated.</p>	NHS England and NHS Improvement will commission a national campaign to promote awareness of the risk that constipation can pose to people with a learning disability, and how it may be prevented, recognised and treated.

Programme	LeDeR findings	Actions completed to date	Action plan
Respiratory	<p>The most frequent causes of death amongst people with learning disabilities, by ICD-10 chapter, are diseases of the respiratory system (19%).</p> <p>Respiratory causes of death in the general population are lower at 14%.</p> <p>A greater proportion of young people aged 18-24 years with learning disabilities die from disorders of the respiratory system compared to young people in the general population (aged 15-24 years).</p> <p>The medical conditions most frequently cited anywhere in Part I of the Medical Certificate of Cause of Death were: pneumonia (25%), aspiration pneumonia (16%).</p> <p>Pneumonia and aspiration pneumonia are causes of death more frequently reported in people with severe or profound and multiple learning disabilities.</p> <p>A significantly greater proportion of people who died from aspiration pneumonia did so between October – December (37%, n=116) than did those without aspiration pneumonia (31%, n=498).</p> <p>Aspiration pneumonia is more frequent in males (18%) than females (14%), in adults (16%) compared to children (6%), and in people with severe or profound and multiple learning disabilities (24%) compared to mild or moderate learning disabilities (14%).</p>	<p>NHS England has established a new national working group, to develop and promote resources to improve dysphagia management, and reduce preventable mortality resulting from the condition.</p>	<p>NHS England and NHS Improvement will continue to work with PHE to ensure that all vaccination programmes are designed to support a narrowing of health inequalities and that this is reflected within provider contracts.</p> <p>During 2019/20 NHS England and NHS Improvement central and regional teams to continue to work with PHE to raise awareness to improve the take up of flu immunisation for people with a learning disability and social care staff supporting people with a learning disability through joint and clearer communications.</p> <p>For 2020/21 NHS England and NHS Improvement to consider whether family carers should also be eligible for flu vaccinations.</p> <p>The NHS England and NHS Improvement cardio vascular disease (CVD)-respiratory programme will focus on understanding and reducing health inequalities amongst people with a learning disability, in collaboration with the learning disability programme. An independent expert will be commissioned to conduct an in-depth review of research evidence and LeDeR programme findings relating to deaths due to aspiration pneumonia and pneumonia (infective) amongst people with a learning disability. This work will report to the CVD-respiratory programme board and inform the board's activity to address inequalities amongst this patient group.</p>

Programme	LeDeR findings	Actions completed to date	Action plan
Sepsis & identifying deterioration	<p>Sepsis is the third most common cause of death amongst people with a learning disability.</p> <p>Deaths from sepsis account for 7% of deaths overall.</p> <p>The rate is likely to be higher due to under-reporting and recognition of sepsis.</p> <p>Where gaps in service provision were highlighted, sepsis was a cause of death in 10% of deaths.</p> <p>Where no gaps in service provision were highlighted sepsis was a cause of death in 5% of deaths.</p>	<p>A national working group has been formed to focus on improved identification of acute deterioration, including sepsis amongst people with a learning disability.</p> <p>Easy read materials, videos and a pop song to raise awareness have been developed to improve awareness and vigilance to the signs of sepsis amongst people with a learning disability.</p> <p>NHS England and NHS Improvement commissioned the self-advocacy theatre company Mixit to develop a short play on the identification of deterioration and sepsis to raise awareness amongst professionals, families and people with a learning disability.</p>	<p>The cross system-sepsis board will continue to include a specific focus on people with a learning disability in all work-plan items for 2019/2020 and ensure that this work is widely shared via a proactive communications strategy.</p> <p>Continue to increase awareness of sepsis amongst healthcare workers including education for community pharmacists, health visitors, community nursing and care home workers, including a focus on people with a learning disability.</p> <p>Develop a surgical sepsis dashboard that identifies patients presenting on surgical wards and via A&E departments. Explore the potential for flagging people with a learning disability within this.</p>

Programme	LeDeR findings	Actions completed to date	Action plan
Medication	<p>19% of people were prescribed antipsychotic medication at the time of death.</p> <p>Most (73%) people taking anti-psychotic medications were only taking one type, but 27% were taking more than one type, including 20 people taking two different types, 6 taking three types and 1 person taking four types.</p> <p>There was an increase in the proportion of adults taking antipsychotics with age: 90% of those taking antipsychotics were aged 50 or over.</p>	<p>NHS England and NHS Improvement launched STOMP (stopping the overmedication of people with a learning disability, autism or both) and STAMP (supporting treatment and appropriate medication in paediatrics) to make sure that people with a learning disability, autism or both are only prescribed the right medication at the right time for the right reason.</p>	<p>Clinical pharmacists in Primary Care Networks will help to increase the overall capacity of the general practice team but specifically, support a range of medicines optimisation activities to improve patient care and safety including delivering Structured Medication Reviews for high-risk patients to address issues such as over-medication. This may include, where clinically appropriate, some patients with learning disabilities. The additional clinical pharmacists in general practice will complement – not replace - existing specialist pharmacy support for patients with learning disabilities, liaising with those services as appropriate to ensure joined-up care for this vulnerable patient group.</p> <p>From April 2020, all Primary Care Networks will implement the requirements of a new national Medicines Review and Optimisation Service Specification which will set out the actions that networks should take to improve the way that medicines are prescribed and managed within primary care. The detail of the Service Specification is being developed during 2019 in collaboration with key stakeholders.</p>

Programme	LeDeR findings	Actions completed to date	Action plan
DNACPR & cause of death	<p>19 reviews reported that the term 'learning disabilities' or 'Down's syndrome' was given as the rationale for a DNACPR order.</p> <p>15 people with learning disabilities had their underlying cause of death erroneously coded as 'developmental disorder of scholastic skills, unspecified' – a commonly used code for 'learning disabilities'. Six of these had been discussed with a coroner - suggesting that a lack of training and knowledge and potential for 'diagnostic overshadowing' extends across primary and secondary care and into the coronial service.</p>	<p>NHS England and NHS Improvement's national medical director has written to NHS provider and CCG chief executives to emphasise strongly that:</p> <ul style="list-style-type: none"> • it is not acceptable for 'learning disability' or 'Downs syndrome' to be cited as the rationale for a 'do not attempt cardiopulmonary resuscitation order (DNACPR). • 'developmental disorder of scholastic skills, unspecified' should never be recorded as a cause of death. 	<p>NHS England and NHS Improvement will ensure that this advice is being adhered to.</p>

Programme	LeDeR findings	Actions completed to date	Action plan
NHS Improvement standards	Not applicable	<p>The learning disability team at NHSI have worked with NHS provider trusts to develop a self-improvement toolkit relating to premature deaths.</p> <p>The toolkit provides clinical staff and managers with an assessment tool for measuring how well they are fulfilling the necessary processes to minimise the likelihood of preventable deaths.</p> <p>The toolkit can be used as a training aid and automatically generates ratings against a number of measures, all of which are based on current policy and align directly with the LeDeR methodology.</p>	The toolkit is a free resource and will be published at the end of May and downloadable via the learning disability improvement hub.
Health checks	Not applicable	<p>NHS England and NHS Improvement have worked with partners including VODG, RCGP, Mencap, NDTi, PHE and others to improve the quality and uptake of annual health checks.</p> <p>A new national template has been introduced into GP practices in England making it easier for annual health checks to be done, and done well.</p>	The Long-Term Plan states that NHS England and NHS Improvement will improve uptake of the existing annual health check in primary care for people aged over 14 years with a learning disability, so that at least 75% of those eligible have a health check each year.

ANNEX 4: Local service improvement examples

Service improvements in acute hospitals

- Hospitals across England have introduced a range of new initiatives in response to learning from LeDeR reviews:
- A number of hospitals across the country have focused on increasing the availability of reasonable adjustments to reduce delays in blood tests.
- Circle of Support meetings involving a learning disability liaison nurse and the patient's circle of support, have been introduced by the London North West Healthcare NHS Trust for anyone with a learning disability, autism or both admitted for more than five days. This means that the person's progress can be reviewed, treatment can be planned, and the right kind of support is in place before the person goes home. It also makes sure that people do not stay in hospital any longer than is necessary.
- Wexham Park Hospital developed a new acute liaison nurse post as the learning from completed LeDeR reviews provided compelling evidence of the value of this role. They have developed a training presentation for all staff to raise awareness and understanding of the need for reasonable adjustments when supporting people with a learning disability.
- Frimley Health NHS Foundation Trust acute hospital has developed a new learning disability strategy, which sets out the principles for supporting people with a learning disability and their families and carers. It also sets out clearly defined roles, responsibilities and assurance requirements for the support of people with a learning disability.
- East and North Hertfordshire NHS Trust is trialling the use of purple wrist bands for people with a learning disability to remind staff to make reasonable adjustments.
- The Barnet Learning Disability Service worked with the Royal Free Hospital Learning Disability liaison nurse to design a discharge prompt sheet for care providers, to ensure good discharges from hospital. This aims to reduce discharge issues by prompting to ensure that all needs will be met when the person returns home.
- Kingston Hospital has set up an Acute Care learning disability collaborative to improve access and support for people with a learning disability when they attend and are discharged from hospital. The work includes improved identification of people with a learning disability and brings together a range of local knowledge to support better care and resolve local issues.
- Bristol Royal Infirmary has begun to involve experts by experience in reviewing the resources and literature used by the Trust to ensure that they are accessible.
- In Stockport, learning disability awareness training has been rolled out for all hospital staff.
- Tameside have increased the number of hospital passports on their patient record system from 64 to 160. The community learning disability team is working to ensure people have an up to date hospital passport that is reviewed to make sure it remains fits for purpose.
- The Greater Manchester Mental Health Foundation Trust (GMMH) and Cheshire and Wirral Partnership NHS Foundation Trust (CWP) have aligned and co-located their liaison services to improve access to timely specialist mental health, learning disability and autism liaison service on their acute sites.
- Imperial College Healthcare NHS Trust has changed its 'purple pathway' to include automatic referral to speech and language therapy for patients with a history of aspiration pneumonia. The discharge pathway similarly includes a 'high risk of return' alert for patients with constipation, aspiration and swallowing problems. These pathways will alert staff to the risks identified through LeDeR and improve patient care.

- The Breast Screening Pathway for women with a learning disability at Northamptonshire General Hospital was redesigned to provide a fail-safe for those who have not been able to have an adequate screen when attending the breast screening unit.
- Staff from North Staffordshire Combined Healthcare NHS Trust and University Hospital North Midlands NHS Trust reviewed and standardised 'hospital passport' documentation for North Staffordshire and Stoke-on-Trent. This should increase familiarity among all local health and social care service staff to improve use of the documentation and access to reasonable adjustments and personalised care.
- Royal Cornwall Hospital Trust have designed an easy read Sepsis leaflet to highlight when to escalate. The leaflet is designed to be used in hospital and in the community where it is hoped that it will prompt patients to be seen by a doctor sooner.
- The Royal Cornwall Hospital Trust have produced a training video describing the death of a child from sepsis from a parent's perspective. The video is designed to give health professionals a better understanding of the importance of making reasonable adjustments and how bereaved parents may feel following a death.

Service improvements in community learning disability teams

- Across England, community teams are doing audits to make sure that everyone they care for has an up-to-date hospital passport which includes everything they need to make sure they get the right support and reasonable adjustments when they go to hospital.
- Some community teams have introduced care co-ordinators for people with complex health problems because poor communication and co-ordination of people's care has been highlighted in local LeDeR reviews.
- A number of teams have developed accessible information for people with a learning disability and plain English resources for family carers and paid carers so that people know more about specific health conditions and how to prevent them or manage them. Many of the resources are being shared across the country so that more people can use them.
- Some teams have developed lists of people with a learning disability who also have significant physical health needs. This means that people have a personal action plan which supports them to stay well or to access the right care if it is needed.
- In Barnet and Haringey, the community learning disability team are working with district nursing, phlebotomy, primary care and acute hospitals on a quality improvement project to improve access to blood tests for people with a learning disability and ensure that they can access the service in a timely manner.
- Worcestershire Health and Care NHS Trust introduced a bowel management plan and pathway following a high number of A&E attendances for constipation. It is expected that this will result in a reduction in A&E attendances, emergency admissions and premature deaths caused by bowel obstruction linked to constipation.
- North Staffordshire Combined Healthcare NHS Trust have created a video to explain the annual health check to people with a learning disability and to encourage them to attend. The team hope that this will increase the uptake of annual health checks in the area.
- In Barnet, the community learning disability team have developed 'start the conversation' packs to support care providers to talk to people with a learning disability about advanced care planning. The team is aiming to empower the people who know the individuals best to have these sensitive conversations, improve the confidence of care providers to advocate for service users and to reduce referrals to the nursing team.

- Enfield integrated learning disability service have agreed to work with the North London Hospice to create an accessible factsheet on palliative care. The aim is to create a clearer understanding of the broader role of the hospice and palliative care and make it more accessible to people with a learning disability.
- Camden integrated learning disabilities service have developed medical information with jargon busters for service users, support workers and families to improve communication, reduce anxiety and support decision making.
- Haringey Learning Disabilities Partnership is developing a complex physical health pathway to reduce the risk of hospital admissions, help to maintain and improve health and improve quality of life for adults with learning disabilities.
- The Ealing Learning Disability Team have employed a permanent member of staff to act as case coordinator for all continuing healthcare eligible clients. This will give families a single point of contact for their relative's healthcare and will enable access to support without having to repeat their story.
- The Oxfordshire learning Disability team has developed a resource for support workers to identify a deterioration in an individual's health needs and decide who, when and how to escalate. This will ensure timely and appropriate interventions through increasing support worker confidence in recognising significant deterioration in an individual's health.
- Ealing Community Learning Disability Team have started to write a Complex physical healthcare policy aiming to have a more co-ordinated approach to care, prevent reoccurring hospital admissions and prevent premature death. They also have a complex care database whereby they RAG rate people's health.
- Ealing Community Learning Disability Team are in discussion about implementing 'Frequent Flyer' Care Plans for people with a learning disability who have reoccurring hospital admissions. This will reduce recurring hospital admissions and ensure prompt discharge.
- Ealing Community Learning Disability Team has created an End of Life Plan which aims to normalise discussions about end of life care with people with a learning disability and improve choice and dignity.
- The Sheffield Community Learning Disability Team re-developed their dysphagia pathway to include a greater emphasis on positioning. They strengthened the joint working between the dysphagia team and physiotherapy and multidisciplinary posters were produced entitled "when to refer" and "safe seating for a safer swallow". The posters have been shared with service providers and individuals and photographs of safe positioning have been included in the pathway.

Service improvements in primary care

- Many GP surgeries are making changes to the way they care for people with a learning disability:
- Camden CCG planned and funded a training session for GPs on the Mental Capacity Act, to improve their knowledge, skills and confidence when using the act. The session also promoted the use of a new template within GP record systems, to further support GP's in writing up capacity assessments, best interests decisions, powers of attorney and deputyships.
- Gloucestershire have introduced a method for capturing carer feedback within the GP annual health check, by introducing a questionnaire that family or paid carers can complete with an individual prior to their annual health check.
- NHS Kingston and Richmond Clinical Commissioning Group working with Richmond Mencap

and NHS England, produced a video for GPs and their teams about making the quality of care better for people with a learning disability and how they can help to reduce health inequalities. This has been shared with GP surgeries across England and is available here: www.youtube.com/watch?v=ZLn4qEM5X4c

- A Gloucestershire learning disability and autism GP champion is leading a pilot tele-health project with partners in the local learning disability team, which aims to gather baseline health readings such as temperature, blood pressure and respiratory readings for people with a learning disability who are also frail. Further evaluation is required, but it is hoped that this will make it easier to monitor normal readings, to flag when problems arise, to increase the confidence of staff in monitoring the health of this vulnerable group and to help in the creation of treatment escalation plans.
- In Staffordshire and Stoke on Trent, the CCGs have been working closely with community learning disability nurses to increase the uptake and quality of annual health checks, including making reasonable adjustments for people with a learning disability in primary care and following up non-attendance.
- The South West sustainability and transformation partnership team is working towards having a 'champion' in each GP surgery to support people with a learning disability and their families. This will enable people to have a single point of contact who knows their story and needs who can provide support and reasonable adjustments.
- In Oldham, greater engagement with GPs is being used to improve uptake and quality of annual health checks. A plan for the coordinated delivery of health checks for individuals who have proven challenging to engage has also been developed. Practices have been offered education events and training to support staff in delivering annual health checks and in making reasonable adjustments. They have also developed a 7-minute briefing for practices and providers around annual health checks which includes key learning from LeDeR.
- Salford and the North West training and development team are working with people with a learning disability and their families to look at promoting registration on GP registers, to ensure that everyone is registered and can receive their annual health check. This will improve access to physical healthcare and will make sure that practices offer reasonable adjustments.
- In Stockport a, learning disability Liaison nurse is working with GPs and parent groups to promote the use of health action plans. Articles about aspiration and cancer screening were published in the GP and CCG newsletter and people with a learning disability have been encouraged to have their flu jab.
- Stockport have completed a data cleansing exercise across all surgeries to support correct identification of people who are eligible for annual health checks. All surgeries in Stockport are now offering annual health checks to everyone on their learning disability register.
- Tameside is undertaking an exercise in the promotion of annual health checks. This includes awareness raising with key groups, distributing leaflets to individuals and carers and an event for people with a learning disability and their families and carers. A GP annual health check and health improvement resource pack has also been developed and distributed to all practices along with training opportunities, to increase awareness of the importance of conducting high quality annual health checks for everyone who is eligible. Individual support is also being offered to priority practices around identifying barriers, improving processes and increasing uptake and quality.
- Suffolk have developed an easy read pre-annual health check questionnaire to improve preparation for the annual health check and ensure that all vital questions are answered.

- Suffolk are developing an annual health check peer educator network to support knowledge and understanding and improve uptake and quality of annual health checks.
- Suffolk are developing a benchmarking and auditing tool and an accreditation system for 'learning disability friendly' GP Practices to standardise and recognise good practice and to improve accessibility.
- Suffolk GPs are now undertaking learning disabilities eLearning Training as well as face to face training to increase awareness and understanding of the needs of people with a learning disability amongst GPs.

Service improvements for family carers and paid carers

- Across England, service improvements are being made that will benefit both family carers and paid carers:
- The Enfield Learning Disability team has introduced a dysphagia fridge magnet to enable carers to identify the signs of aspiration, and to know how to report urgent concerns.
- The Camden Community Learning Disability team introduced an escalation and resolution procedure to empower family carers, paid carers and home managers to raise concerns or challenge clinical care.
- Central London clinical commissioning group arranged a provider event to make sure that providers are clear about how they are expected to support residents when they are in hospital.
- In Gloucestershire, a "was not brought" flag has been introduced into community NHS services. The "did not attend" protocol has been updated, to reflect that some people with a learning disability are unable to attend appointments unless someone goes with them. Joint commissioners funded 'Inclusion Gloucestershire' to develop a film to support this initiative, working with safeguarding colleagues <https://www.youtube.com/watch?v=jK7YaXoC5dc&feature=youtu.be>
- Oxfordshire commissioned a workshop for paid carers on identifying deteriorating health in people with a learning disability, and how high-quality care plans and hospital passports can help in these circumstances.
- In Hertfordshire, end of life care training has been provided to supported living staff, to improve confidence to care and support someone who is on the end of life pathway.
- Worcestershire clinical commissioning groups worked with Inclusion North to coproduce workshops and resources for social care staff and family carers. These focused on the health needs of people with a learning disability, including lifestyle issues related to constipation (i.e. hydration, diet, exercise, bowel health and continence management) and spotting signs of deterioration.
- The centre for autism, neuro-developmental disorders and intellectual disability within the Cheshire and Wirral Partnership NHS Foundation Trust has established a training skills hub to provide regular training to carers on physical health.
- Oxfordshire CCG worked with learning disability teams to set up a workshop for support workers and team managers to discuss access to and use of health care services by people with a learning disability. Outputs from the workshop included a set of prompts to give support workers more confidence to seek clarification from clinicians and resources to help support workers assess the needs of a person whose health is getting worse. Peer support networks in localities are being developed so that support workers are able to share concerns.
- Oxfordshire CCG has also promoted the development of proactive links between supported living houses and their local GP practices to better support the health of the people they care for. Some practices have run health education sessions in the supported living environment.

In addition, local hospitals have changed their discharge protocols to ensure plans about discharge are shared with support workers as well as the person with a learning disability and their family. The CCG's work with support workers has improved timely support and responses to changing support needs for individuals.

- Suffolk is developing a Core Skills Framework for support staff working in the field of Learning Disabilities. The framework is competency based and will improve awareness and quality of care.
- In Hertfordshire, end of life training has been delivered to supported living providers. This has resulted in staff feeling more confident in supporting individuals who are close to death and wish to remain in their own homes.
- Arden Transforming Care Partnership has developed a leaflet on identifying constipation in people with a learning disability and have distributed it to all care homes in the area. The leaflet was designed to improve early diagnosis of constipation and promote the health of people with a learning disability.
- Bexley CCG will offer advanced dysphagia training to care homes to improve the knowledge and skill of staff in the management of dysphagia.
- In Hertfordshire, a website has been developed to share accessible information about health. This means that people with a learning disability, families and paid carers will be able to access local health information in one place.
- Worcestershire CCG commissioned the co-production of a resource pack and workshops for paid and family carers on essential aspects of supporting good health for people with a learning disability. This is expected to increase carer knowledge on essential subjects such as nutrition, hydration and how to spot the signs of ill-health.
- Islington Learning Disability Partnership are intending to make better use of genealogy services to trace estranged relatives and inform them of a person's death. The aim is to raise awareness of these services and, with consent, to use them to trace estranged relatives.
- Salford held a 'Big Health Day' to raise awareness of physical health issues amongst people with a learning disability and their families and carers.
- Suffolk clinical commissioning groups have produced several easy-read health resources to support understanding of health issues amongst people with a learning disability and their families and carers.

Other service improvements

- A number of areas across the country have held learning events regarding the learning from specific reviews to make sure that the learning is shared widely across health and social care and that agreed service improvements and best practice developments are sustained.
- Across health and care, services are focusing on helping people with a learning disability get used to healthcare environments and the treatments that make them anxious, so that they can be more relaxed when they need treatment more urgently.
- A number of services across the country are reporting that there is more engagement and involvement of commissioners because of the completed LeDeR reviews in their area.
- Other initiatives have been introduced at a local level across England:
- Cheshire and Merseyside have developed a dysphagia protocol guidance document for managing dysphagia, which links to a safeguarding pathway and alerts staff to the need to consider capacity and best interests.
- Services in Gloucestershire have recommended to the council highways department that road calming measures designed to slow traffic are required where vulnerable people with a learning disability are known to cross frequently. They have also funded 'Inclusion

Gloucestershire', to develop a set of resources to support people with a learning disability to use public transport and the roads safely.

- In Derbyshire, a series of constipation awareness sessions have been delivered across the health and care sectors, to support better understanding of risks, prevention and management.
- Gloucestershire are piloting reasonable adjustments to enable people with a learning disability to access mainstream healthy lifestyles interventions such as smoking cessation, weight management and eating well. The pilots aim to increase knowledge and understanding of the impact of healthy lifestyles and to improve the accessibility of mainstream services such as dietetics for people with a learning disability.
- In Liverpool a simple pathway has been developed for decision making and safeguarding in adults with dysphagia and a learning disability. The pathway will serve as a guide for all staff to raise awareness and enable a safe and timely approach to safeguarding and mental capacity act aspects of care for this vulnerable group.
- The North East and North Cumbria LeDeR steering group has set up a parallel confirm and challenge group made up of people with a learning disability and family carers. The group are equal partners and allies of the LeDeR steering group, so that the voice of experts by experience is central to the learning into action work.
- Knowsley Safeguarding Adult Board has developed guidance on undertaking risk assessments with people with a learning disability who are not engaged and lack capacity to make the decision in focus.
- NHS Wandsworth and Merton CCGs hosted a learning event for family carers and professionals, to share the learning from LeDeR reviews, raise awareness about the LeDeR programme and develop the local 'learning into action' strategy.
- road calming measures designed to slow traffic are required where vulnerable people with a learning disability are known to cross frequently. They have also funded 'Inclusion Gloucestershire', to develop a set of resources to support people with a learning disability to use public transport and the roads safely.
- In Derbyshire, a series of constipation awareness sessions have been delivered across the health and care sectors, to support better understanding of risks, prevention and management.
- Gloucestershire are piloting reasonable adjustments to enable people with a learning disability to access mainstream healthy lifestyles interventions such as smoking cessation, weight management and eating well. The pilots aim to increase knowledge and understanding of the impact of healthy lifestyles and to improve the accessibility of mainstream services such as dietetics for people with a learning disability.
- In Liverpool a simple pathway has been developed for decision making and safeguarding in adults with dysphagia and a learning disability. The pathway will serve as a guide for all staff to raise awareness and enable a safe and timely approach to safeguarding and mental capacity act aspects of care for this vulnerable group.
- The North East and North Cumbria LeDeR steering group has set up a parallel confirm and challenge group made up of people with a learning disability and family carers. The group are equal partners and allies of the LeDeR steering group, so that the voice of experts by experience is central to the learning into action work.
- Knowsley Safeguarding Adult Board has developed guidance on undertaking risk assessments with people with a learning disability who are not engaged and lack capacity to make the decision in focus.
- NHS Wandsworth and Merton CCGs hosted a learning event for family carers and professionals, to share the learning from LeDeR reviews, raise awareness about the LeDeR programme and develop the local 'learning into action' strategy.

