Learning Disability Mortality Review (LeDeR) programme:

Action from Learning Report 2019/2020

Tracking Reference: 2002171623RD
Title: NHS England and NHS Improvement Action from Learning report describing progress to address premature mortality and health inequalities of people with a learning disability.

PAC Decision: Approved

Publishing approval reference: 001492

This document is available in easy read and can be provided in alternative formats on request.

Publication date: July 2020

Contents

Acknowledgements

As always, we are deeply indebted to families for their courage, strength and insights in working with us to improve the LeDeR programme by contributing to the reviews of the deaths of their loved ones. Without their willingness to share their experiences for the benefit of others, we would not have made the progress we have, either in developing a greater understanding about what people with a learning disability and their families need us to do, or in translating that learning into action.

NHS England and NHS Improvement would like to thank the University of Bristol for their dedication and hard work in supporting the LeDeR programme. The University of Bristol will continue to work with NHS England and NHS Improvement for the coming year to help take forward the LeDeR programme and continue this invaluable work.

We are grateful to Ruth Bell, Lead Nurse for Learning Disability and Autism at the Northern Care Alliance NHS Group and members of Oldham Personal Advocacy Ltd and Pennine Treat Me Well group for their permission to use their photographs in this report.

In memory of Karl Butler

This LeDeR Action From Learning report is dedicated to Karl Butler who died suddenly in the last days of June.

Karl was a Learning Disability and Autism Adviser and a valued and respected member of the LeDeR team in the National Learning Disability and Autism programme. He had worked for the NHS for over three years – first with the East of England regional team before joining the national team.

An inspirational, passionate, thoughtful and considered advocate, Karl used his own experiences of healthcare to drive and inspire others to be agents for change to address the health inequalities of people with a learning disability. It was a dream of Karl's to work in the national team at NHS England and NHS Improvement, and as one of our colleagues put it, 'he lit a fire under everyone he met to make things better'.

"I have the determination of making things right for people [so] that they can have a good, ordinary life".

Despite having complex health conditions throughout the course of his life Karl (or KB as he liked to be called) lived his life to the full. During his short life, he was involved with the Princes Trust, worked with local councillors, self-advocates and commissioners, and achieved qualifications in health and social care. He loved music and festivals immensely, played the drums and was a DJ. He loved Manchester United and also went to Wimbledon.

There are some people who touch our lives in incredible and unexpected ways. They don't have to be the loudest or the strongest, but they quietly affect the way we feel, the way we relate to others and the way we want to be.

Karl had a unique insight, and the ability to translate ideas and concepts into meaningful action, always considering the bigger picture. He will be a loss to the whole NHS. Those of us who worked with him will strive to emulate his approach, so that Karl's influence continues to contribute to making the world a better place for everyone who is autistic or who has a learning disability.

Foreword from NHS England and NHS Improvement

We welcome the fourth report from the Learning Disability Mortality Review (LeDeR) programme. LeDeR was commissioned in 2015 with the aim of contributing to the improvement of quality of care and health outcomes for people with a learning disability.

We know that too many people with a learning disability die too young and as this programme continues we understand more about the circumstances that led up to those deaths. There is much more we need to do and the LeDeR programme gives us the largest body of evidence in the world about the deaths of people with a learning disability reviewed at an individual level.

The success of the LeDeR process is, of course, dependent on the support of the family members and carers of those who have died and the inclusion of personal stories in this report is a poignant testimony to them and their loved ones.

This report includes actions taken at a national level and a number of examples of improvements in local areas from across the country. Thank you to everyone who has helped make these changes happen, especially the people with lived experience so often making the most important contribution to this vital work.

The issues around healthcare of people who need our care and support, their families and carers has been further heightened in recent months by the COVID-19 pandemic. NHS England and NHS Improvement are working closely with its partners to to understand the impact of the pandemic on people with a LD and how we can make changes to services to help ensure that we do all we can to reduce health inequalities. We remain committed to the LeDeR process in driving local change.

NHS England and NHS Improvement will continue to work with the University of Bristol for a further year to deliver LeDeR and we will be talking to stakeholders, families and carers, and health and care services to understand what is working well and what is needed to improve the programme.

Whilst we can always learn more, what matters is the changes that are made as a result of that learning; we can and we must do more with and for people with a learning disability and their families/carers.

The LeDeR process and its reports are the way we:

ASK what needs to change and how
LISTEN to the compelling evidence
DO all that each of us can to make much needed changes and improvements.

Please don't let this be just another report, every reader has a part to play in making a difference.

Ray James - National Director, Learning Disability and Autism

Roger Banks - National Clinical Director, Learning Disability and Autism

Karl Butler - Learning Disability and Autism Adviser in Health Improvement

What you will find in this report

This action from learning report details just some of the work that has taken place across the NHS over the past year in response to findings from reviews of deaths, with further examples provided via the Learning Disability Mortality Network on NHS Futures. For information on how to access this network, please see the helpful resources document published alongside this report.

It contains information and examples of good practice at both a national and local level to show the things that have been learnt from the reviews so far of deaths of people with a learning disability and the changes that have happened and are planned as a result of that learning.

The report also provides details of the actions taken to address the key clinical priorities identified from last year's LeDeR report namely: respiratory conditions, sepsis, reducing hospital admissions for people with complex care needs, constipation and cancer screening.

The table in Appendix 1 summarises our response to the recommendations from last year's report from the University of Bristol report. Detailed information about how your local area is responding to the findings of deaths that have been reviewed locally, can be found in your Clinical Commissioning Group or LeDeR steering group's annual report. Many of these annual reports have been delayed as a result of COVID-19 but all reports will be published by the end of September 2020. Links to reports available at the time of writing can be found in Appendix 3.

Progress made by the Government and other arm's length bodies can be found in their national updates. Links to these updates can be found in the helpful resources document.

The LeDeR annual report is published in Spring each year following a review of the deaths which were completed in the preceding calendar year. So, the third University of Bristol report which this document is based on covers deaths that were reviewed in the calendar year 1 January 2018 to 31 December 2018 and is referred to throughout this document as the '2018 report'.

The Fourth LeDeR annual report, published alongside this Action from Learning Report published in 2020, covers LeDeR reviews completed between 1 January 2019 and 31 December 2019 and will be referred to throughout as 'the 2019 report'.

Action from learning: Nick's story and Gloucestershire's project to improve nutrition

Nick was the eldest of four and lived with his mum as his main carer until he was 52 when she was diagnosed with breast cancer and he moved to supported living. His mum phoned and visited him frequently until her death in 2017.

Nick had a mild learning disability and cerebral palsy. He communicated using Makaton and his own signs and gestures.

He loved horse riding and won 46 riding certificates in dressage. He liked to swim and loved car trips and holidays, spending time with his family and watching TV – especially films and football.

Family, friends and carers said his health deteriorated after his mum's death. He died at home in January 2018.

Nick died from malnourishment. He had dysphagia and aspiration pneumonia and his death may have been prevented had care staff had greater awareness of dysphagia, the importance of eating well and better knowledge of weight management and monitoring.

He was admitted to hospital in early December 2017 for nutritional treatment and assessment. Discharged on the 19th December, he was placed on a palliative care plan the following day with a do not attempt cardiopulmonary resuscitation (DNACPR) order.

One of the things the LeDeR review of Nick's death showed was that although his hospital passport detailed his needs in terms of eating, communication aids and reasonable adjustments for his care, his eating needs were not properly met.

Eating was the reason he was in hospital and an appropriate level of additional caution and support was to be expected. However sometimes he was given un-thickened fluids without appropriate feeding equipment, had limited supervision during mealtimes and few reasonable adjustments were made to enable him to eat safely.

What Nick's death also highlighted was that community staff had limited access to sit-on or sling scales which had led to an inaccurate record of Nick's weight. By the time a problem was recognised, Nick had been too unwell and his weight too low for him to be anaesthetised safely to have a percutaneous endoscopic gastrostomy tube (PEG) inserted into his stomach to feed him.

The findings from Nick's review, together with themes identified through other LeDeR reviews across Gloucestershire, have led to changes.

Since 2018, around 300 carers have been trained through a specialist course commissioned from Gloucestershire Health and Care NHS Foundation Trust by Gloucestershire integrated disabilities commissioning hub – a partnership of Gloucestershire Clinical Commissioning Group and Gloucestershire County.

The two-day Eating Well course, delivered by a specialist dietitian and developed using materials from the Caroline Walker Trust, helps carers to support people with obesity, malnutrition, diabetes, dysphagia, selective eating habits and coeliac disease.

It includes interactive workshops looking at portion sizes, changing recipes, menu planning and the behaviours people may exhibit in relation to food. It also includes modified texture diets and thickened drinks, eating out, and what to do when someone is off their food or has a poor fluid intake.

Further planned action in Gloucestershire includes:

- A full clinical review of the eating and drinking PEG pathway for people with a learning disability
- Recruitment of a specialised dietician to the intensive health outreach team
- Clearer information about the where to find and use of appropriate weighing scales for people who need to sit down or use a wheelchair and the importance of recording accurate weight
- A co-produced conference with local people with a learning disability and their families for health and care staff in hospital and community services focusing on dysphagia, management of choking, risk identification and spotting the signs of aspiration pneumonia.

A final word from Nick's brother Mark who believes there would have been a different outcome if his brother hadn't had a learning disability. Mark calls on professionals to listen to family members and carers because they know the person being cared for better than anyone else.

"I hope the LeDeR process will support other people going forward and as a result that changes will be made to practices in the future. The reviewer did an excellent job, dug deep and got an outcome."

Action from learning in 2019/2020

Respiratory conditions

Respiratory conditions remain the most significant causes of premature mortality for people with a learning disability where deaths have been reviewed as part of the LeDeR programme. Bacterial pneumonia was stated as a cause of death for 24% of adults and 20% of children whose deaths were notified in 2019/20, with aspiration pneumonia cited in a further 17% of adult and 3% of children's deaths. In total, these respiratory conditions accounted for 2,162 deaths of people with a learning disability.

NHS England and NHS Improvement are working with the British Thoracic Society to develop of an 'ideal pathway of care' for adults with a learning disability who have pneumonia. The two clinical statements, due for completion in early 2021, will cover the core principles of care and positive practice for prevention, looking after yourself, and treatment in primary and community services as well as hospitals.

During the flu campaign for Winter 2019/20 we focused on improving access for people with a learning disability, their families and social care staff who support them.

An easy read flu leaflet and poster, supported the national Immunisation & Stay Well this Winter Campaign and raised awareness about why flu vaccination is important. A template easy read letter to invite people with a learning disability for a flu vaccine is also available from the Gov.uk website.

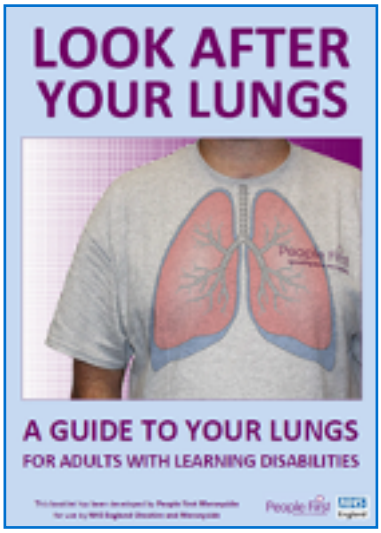
The campaign was supported by stakeholders including Mencap, as well as local partnerships and services. As well as work nationally, local areas are also prioritising improvements around respiratory pathways and services. There are some good examples of changes happening.

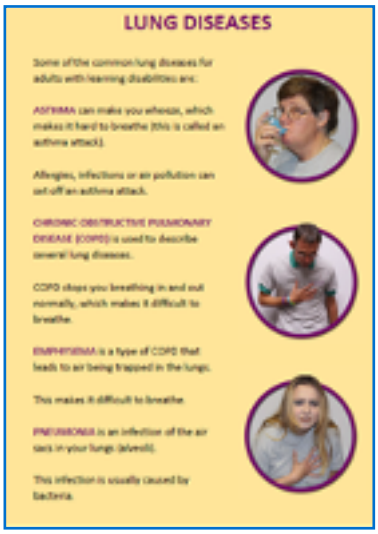
Lung health campaign in Merseyside

In the North West, the self-advocacy group People First Merseyside developed a lung health campaign aimed at adults. It includes a booklet with advice about respiratory care, lifestyle factors, tips on eating healthily as well as breathing exercises because members didn't know what their lungs were for or how lung conditions might impact their health.

Most members rarely did activity that would make them out of breath or raise their heart-rate so breathing and stretching exercises were introduced and they were encouraged to 'dance like nobody's watching' to give their lungs a workout.

To reinforce the messages explained in the booklet, lung health training has been built into the wider red flag cancer training being delivered across the North West by People First Merseyside.





Oral care project in South London

Tooth decay, frequency of brushing and dependence on others for oral care is associated with pneumonia due to increased levels of oral bacteria in the saliva (Langmore, et al, 1998). This is why speech and language therapists at Your Healthcare Community Interest Company in Kingston and Richmond in Surrey include oral health care as an important part of eating and drinking assessments and support people to attend regular dental check-ups.

During 2019, with advice from the local specialist dental team, the therapists organised training for staff at residential homes about oral health and the types of reasonable adjustments needed to help people attend dental appointments. These include arranging for people with a learning disability to visit the surgery and meet the dentist prior to their appointment. The team also identified a need for practical advice on how to clean someone's teeth where they are reluctant. Workshops arranged to provide this training were delayed because of COVID-19 and will be held later in the year. Feedback from participants will help improve the training and the team is also considering how to provide bespoke packages of advice and training to specific residential homes.

The Speech and Language therapy (SALT) team is also working with providers of support to people with learning disabilities who are living independently or semi-independently by offering practical tips and explanations, such as explaining why the cheapest toothbrush isn't necessarily the best option and how to support people to make positive choices around their oral and dental care.

Dysphagia training in Hertfordshire

Dysphagia is one of the key causes of aspiration pneumonia. In Hertfordshire, the speech and language therapy and dietetic service is offering free dysphagia training to carers of people with a learning disability. One hundred and sixty-eight people have attended the training in care homes across Hertfordshire and their positive feedback has meant that training previously held once every three months for half a day has now increased to a full day every other month.

Sepsis

Sepsis is a life-threatening reaction to an infection. It happens when your immune system overreacts to an infection and starts to damage your body's own tissues and organs. Sepsis is sometimes called septicaemia or blood poisoning.

In the 2018 report, sepsis was identified as the second leading cause of death for people with a learning disability whose deaths were reviewed as part of the programme. NHS England and NHS Improvement's patient safety programme is now putting in place measures that record acute deterioration in people with a learning disability and the cross-system sepsis board has introduced a learning disability digital flag in all sepsis datasets and developed easy-read materials for the NHS website.

Identification tools, such as NEWS2 and RESTORE2™, have been shared across the health system to help carers and clinical teams flag when a person may be becoming ill or deteriorating. An evaluation of the use of early warning score systems has been commissioned by NHS England and NHS Improvement with preliminary results expected later this year. From this evaluation we will be able to determine how the toolkits can be rolled out nationally.

Health Education England (HEE) commissioned the UK Sepsis Trust to develop a training programme for family carers and non-clinical staff to raise awareness of signs and symptoms and increase the confidence of families and carers to raise concerns. The course, which includes face-to-face and online support, was piloted across the North of England this year. The online support including an introductory film to spot the signs of deterioration and serious illness such as sepsis and a video on the 'soft' signs of deterioration is available for everyone to access.

In Hertfordshire, a dedicated team has been set up to identify and produce accessible sepsis resources. An 'Easy Read Signs of Sepsis Information' leaflet has already been co-produced and a well-established guide (Top to Toe) to support early recognition of the signs and symptoms of ill health in people with a learning disability is being updated.

Purple All Stars (a creative arts group of people with a learning disability) has produced a song on sepsis which they are promoting via live performances and social media. This is aimed at people with a learning disability who may not access other sources of health information.

Preventing people from going into hospital unnecessarily (avoidable admissions)

Complex care in South London

The complex health pathway developed by staff at Your Healthcare CIC, who provide community health and social care services in Kingston and Richmond, offers three levels of priority for support based on each person's level of risk. A multi-disciplinary approach gives team members clearer oversight and responsibility for individual patients, e.g. a social worker nurse or allied health professional will act as the key professional for each person.

For Mr B, a 46-year-old gentleman who is non-verbal with a significant learning disability this innovation has improved his quality of life and reduced his admissions to hospital from seven times in 2019 to zero. Mr B's care was provided by a range of professionals including physiotherapy for his complex seating needs, speech and language therapy to manage dysphagia and prevent chest infections, and dietetics to manage his enteral percutaneous endoscopic gastrostomy (PEG).

As the clinician who knew Mr B best, the speech and language therapist took the lead on his care and through a care review and analysis of his medical records, including his GP records, developed a clearer, more holistic picture of Mr B's needs and the reasons for his previous admissions to hospital.

The therapist talked with his care providers and Mr B's family to get a better understanding of his care needs and identified key areas of improvement. Everyone agreed it was important to maintain Mr B's quality of life through activities, including use of a hydrotherapy pool.

Using the pool was identified as an infection risk for Mr B because he used a PEG feeding tube. To mitigate this, nurses drew up an escalation plan so his carers would know what to do in various scenarios and a spare PEG kit was provided in case it needed to be changed.

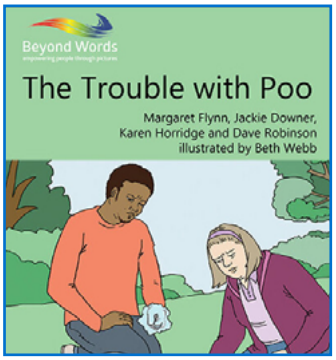
Information about the plan was shared with his residential home to improve the confidence of staff members in caring for him and about where to get help if needed. Information was shared with the hospital teams to avoid the risk of diagnostic overshadowing and to avoid the presumption that physical symptoms were a consequence of a presumed chest infection.

This joined up approach has made a real difference to Mr B's life.

Cheshire and Wirral Partnership NHS Foundation Trust's community learning disability team (CLDT) has developed a tool to identify adults who are at particular risk of admission to an acute hospital. Staff then provide the person who is unwell with a personalised care plan to help prevent their admission.

Building on literature, best practice and insight from five clinical focus groups, the Cheshire and Wirral Partnership team developed an easy to use assessment tool to identify when a person's physical health is deteriorating and the factors that might put them at greater risk of admission to hospital. Developing a risk rating through this helps the team to ensure that people with a learning disability get the support they need for their physical health conditions, and so reduces the risk of admission to hospital and supports people to stay well. The physical health risk assessment tool is being piloted with around 200 people and will be tested further with GPs and primary care services in the area. An independent evaluation has been commissioned by the trust and will be shared nationally.

Constipation



Constipation is easily preventable and treatable. It is unacceptable that, of the deaths reviewed as part of the LeDeR programme in 2018, 12 people died from constipation.

NHS England and NHS Improvement set up a working group on constipation. The group has produced resources highlighting the risk constipation poses to people with a learning disability and how to prevent, recognise, and treat it. NHS England and NHS Improvement also provided funding to 'Books Beyond Words' to produce a book to improve understanding of the risks of constipation and the importance of getting help.

A national campaign by NHS England and NHS Improvement and its partners, highlighting the risks from constipation for someone with a learning disability, is scheduled to launch this year (2020/21) but has been delayed due to COVID-19.

Using the learning from the LeDeR review of the death of a young man who died from constipation, NHS Weston Area Healthcare Trust (WHAT) implemented an awareness and education campaign for their staff about the risks of constipation and benefits of a good balanced diet.

The Trust's learning disability steering group met to discuss the issues with a pharmacist and dietician and how best to raise awareness.

Since the first meeting in early 2019, the team has updated local learning disability (statutory and mandatory) training for health staff, shared the story of the young man, including content on diagnostic overshadowing and non-verbal indicators of pain and discomfort, and raised awareness about the use of pictorial menus that help non-verbal patients to ask for what they want to eat.

Similar work by Cheshire and Wirral NHS Foundation Trust has improved staff training and awareness, where, videos and findings from LeDeR reviews are used to help people understand the risks of constipation, how to recognise the symptoms and treat them early.

Cancer

The rate of deaths from cancer for people with a learning disability (13% for men and 15% for women with a learning disability in 2019) are half that for the general population but the 2018 report showed that, for the deaths reviewed as part of the programme, gaps in services and support for accessing cancer screening may have contributed to the death of 7% of people with a learning disability.

Development of easy read information on cancer screening

Easy read information has been developed to be available nationally including a screening e-learning resource for carers.

Whilst some of this work has been delayed due to COVID-19, however, further resources about accessible screening are available on Public Health England's website, including bowel screening, cervical screening and breast screening information.

Improving access to cancer services in North East and North Cumbria

The Northern Cancer Alliance, a collaboration of providers, commissioners and voluntary sector organisations, is focused on increasing cancer survival across the North East and North Cumbria. As well as hosting events to improve the care of people with a learning disability who have cancer, an outreach service by the acute liaison team at County Durham and Darlington NHS Foundation Trust provides follow up care for people with a learning disability after they have been discharged and a cervical screening information pack.

The pack was produced with practice managers, the community learning disability team (CLDT), Macmillan Cancer Care professionals and members of the screening and immunisation team (SIT) to increase take up of cervical screening and explain the process. It is available online and includes information on capacity and consent, best interest guidance, easy read invite letters for GPs, sample letters for parents and carers and links to national easy read materials. People with a learning disability reviewed the content before it was rolled out to make sure the easy read materials were clear and simple to understand.

The North East and Cumbria Learning Disability Network has developed a quality check list and process for evaluating services to improve cancer screening access for people with a learning disability. Working with Skills for People, the programme employs people with a learning disability and autistic people to visit screening centres and identify how services could be improved. A steering group, including experts from Skills for People, screening centre staff and members of the screening and immunisation team, oversees the work to ensure quality checks deliver consistent results.

Cancer 'red flag' campaign in Merseyside

Improvements to screening and access to cancer services are being implemented in Merseyside, led by People First Merseyside who have designed the 'red flag' symptom awareness campaign. The team have delivered 13 red flag training events across Cheshire and Merseyside, with more than 50 further training sessions planned across the North West and Yorkshire and Humber regions.

Epilepsy

People with a learning disability are much more likely than the general population to have epilepsy:

- About 1 in 3 people (32%) who have a mild to moderate learning disability also have epilepsy.
- The more severe the learning disability, the more likely that the person will also have epilepsy.

Source: Epilepsy Society

The 2018 report identified that a lack of understanding of epilepsy and how to support someone who also has a learning disability may have contributed to 5% of deaths. Guidance published by the Right Care programme in 2020 supports local health systems to reduce inequalities and variations in care.

This epilepsy toolkit was produced with the help of expert stakeholders and NICE to explain the priorities in epilepsy care and key actions to take, with specific guidance for supporting people with a learning disability. Themes covered include education and training for staff, medicines optimisation and risk management. It also supports the assessment and benchmarking of care systems to find opportunities for improvement.

Locally, this work has been implemented in Merseyside. A key recommendation is the recruitment of epilepsy nurse specialists and Alder Hey Children's NHS Foundation Trust is recruiting a learning disability epilepsy specialist nurse to their team. The role, which is based in the community will support children and young people and their families to access support for escalations of behavious that challenge, for example, during medication reviews and changes.

Epilepsy liaison nurses for people with a learning disability are already in post in Exeter where they support people with a learning disability with epilepsy or suspected epilepsy when they go into hospital. This can either be for a planned admission, as an emergency, or as an outpatient. The liaison team deals with any consent issues, and follows the person from admission to discharge, checking that they have what they need and that they understand the information given to them.

Do not attempt cardiopulmonary resuscitation

Whilst there are situations where do not attempt cardiopulmonary resuscitation (DNACPR) directions may be appropriate, the 2018 report raised concerns about instances in which a learning disability was cited as the reason for making a DNACPR order.

As a result of this Professor Stephen Powis, the National Medical Director for NHS England and NHS Improvement, wrote an urgent letter to the NHS system reminding staff that a learning disability is not fatal and should never be used as a cause of death or the rationale for a DNACPR order.

The 2019 report indicates a reduction in the use of DNACPR in those reviews considered as part of that report. Of the thirteen completed reviews in 2019 which cited learning disability as a reason not to resuscitate, eleven happened before Professor Powis' letter on 20 May and only two afterwards, however, the full impact of his letter will take time to be seen. To ensure that this work is embedded across the NHS we will continue to work with the national medical examiner programme to ensure that learning disability is never cited as a cause of death on a death certificate.

COVID-19 has heightened concerns about the use of DNACPR on a 'blanket' basis and or without discussion with the person, their family or loved ones. On 3 April 2020, senior leaders from NHS England and NHS Improvement, Dr Roger Banks, National Clinical Director for Learning Disability and Autism, Claire Murdoch, National Mental Health Director, and Dr Nikita Kanani MBE, Medical Director for Primary Care, sent a joint letter to the system to provide clarity on the use of DNACPR where people have a learning disability or are autistic. The same principles apply to people with dementia. This was followed on 7 April 2020, by a joint letter from Professor Stephen Powis and Ruth May, NHS England and NHS Improvement's Chief Nursing Officer stating that:

'…..each person is an individual whose needs and preferences must be taken account of individually. By contrast blanket policies are inappropriate whether due to medical condition, disability, or age. This is particularly important in regard to 'do not attempt cardiopulmonary resuscitation' (DNACPR) orders, which should only ever be made on an individual basis and in consultation with the individual or their family.'

Action from learning across England

All regions are sharing best practice and learning. For example, in the Midlands, a Birmingham and Solihull stakeholder conference for 120 people shared findings from local LeDeR reviews. Workshops included sessions on end of life care, acute liaison, pain management, and patient experience along with top tips for change for people to take back to their workplace. Members from the local experts by experience group ran workshop sessions during the event.

A series of ten similar events were held across the North of England and attended by more than 500 people. These events were co-produced and co-delivered with people with a learning disability and carers and shared both local and national findings about the work of LeDeR and examples of what teams in the North of England are doing to improve the health and wellbeing of people with a learning disability.

In the East of England learning and sharing events were held in Luton and Hertfordshire. In Hertfordshire 123 people attended the event which focused on ensuring equitable services and care is provided to people with a learning disability whilst in Luton, around 60 people attended to discuss the national and local learning from LeDeR.

Each CCG LeDeR report, as it is published, will include information about how the learning from the deaths of people with a learning disability in the local area is bringing about change in the delivery of health care. Links to these reports (where they have been published) can be found at Appendix 3.

Below we spotlight some of the work happening in just one of our regions to demonstrate the reach of the learning from LeDeR.

Spotlight on the South West

In the South West learning from reviews is improving the health and wellbeing of the region's population of people with a learning disability, primarily through reasonable adjustments and annual health checks.

The sunflower scheme which supports the use of reasonable adjustments was already used at acute hospitals in Gloucestershire and Bristol and promoted across the community in Somerset. The campaign will be expanded across the South West region in the coming year.

Health services across Gloucestershire and Devon piloted a reasonable adjustment flag on their electronic patient records. The flag, linked to the national NHS Spine, aims to make sure clinicians understand how best to make reasonable adjustments to care and how to engage better with people with a learning disability and carers to ensure a positive experience and outcome. A flag might say, for example, that the person with a learning disability uses Makaton to communicate or prefers a male clinician to provide health care.

Areas across the region also run local events to promote LeDeR, such as a healthy lifestyles day in Somerset. This event focused on ensuring healthcare and support staff understood their role in enabling people to make informed choices in the way they live, with a focus on healthy eating and activity.

Other examples include:

- LeDeR reviews driving change to the enteral feeding pathway in Gloucestershire after findings indicated services for people with learning disability and swallowing difficulties could be improved.
- Bristol, North Somerset and South Gloucestershire's learning disability champions network to ensure staff have a contact for any issues or questions and focuses on promoting health checks and reasonable adjustments across the NHS locally.
- A project in Somerset to help care staff support people with a learning disability and their carers to prepare for health checks, including the use of reasonable adjustments.
- A collaboration between health services and a voluntary sector care provider in Devon and Cornwall focused on improving the quality and range of accessible information available to people to address LeDeR findings.

- The launch of a South West learning disability collaborative to improve the uptake of flu vaccination; increase the numbers and quality of annual health checks; and the identification and response to the deteriorating in patients based on positive results from NEWS2 an acute deterioration toolkit.

- A South West network of clinicians to support better care for people with a learning disability and lead work including co-production of an annual health check quality improvement tool. The tool has been tested in Wiltshire, Devon & Cornwall by community learning disability nurses in partnership with GP practices and experts by experience and will be rolled out across the region.

Action from learning: changing how we work

The work highlighted in this action from learning report focuses on what work has been done to address clinical pathways, improve care and reduce avoidable deaths. However, changes to how we work in the NHS – to our systems and processes – also impacts on premature mortality (people dying younger than they should do).

Reasonable adjustments

NHS Improvement's learning disability improvement standards include a requirement for all trusts to make reasonable adjustments for people with a learning disability.

Public Health England has a range of resources on reasonable adjustments for people with a learning disability, aimed at supporting healthcare staff and families and NHS England and NHS Improvement's quality improvement tool measures the quality of hospital care for people with a learning disability and their families and carers.

A national benchmarking survey draws on the views and experiences of people and families, frontline staff and trust managers, to help trusts identify opportunities for improvement and highlight good practice.

The first survey in November 2019 led to the development of a self-improvement tool for trusts, and the second survey, which finished in March 2020, will report later this year.

As a result of stakeholder concerns raised during the COVID-19 pandemic we co-produced a COVID-19 grab and go guide to help frontline clinical staff understand what reasonable adjustments might be needed in an emergency situation. The grab and go guide complements the guide for clinical staff which was also published to support reasonable adjustments for care during the response to COVID-19.

Many local areas are focusing on improving access to mainstream health services by ensuring that reasonable adjustments are made. As well as the Sunflower scheme in South West England, Hertfordshire County Council have worked with a software company to develop a communication app called 'My Health Guide' to improve communication between individuals, the carers who support them and health professionals. The target is to have 1,000 people using the app in 2020, free of charge.

In London, Enfield's integrated learning disabilities service has improved hospital discharge by working with the London A2A Network to produce a 'My hospital visit – information to take home with me' accessible discharge booklet.

The booklet uses easy read language and pictures to help people with a learning disability take notes about their visit, including information on the hospital, which healthcare professional they saw, the reason for their visit, treatment, what was discussed, whether or not they need to return to hospital and what to do if they feel unwell.

Digital 'flag'

NHS England and NHS Improvement are working with NHS Digital to roll out an adaptation to the summary care record system.

The digital 'flag' will alert NHS providers that a particular patient needs 'reasonable adjustments' (defined by the Equality Act 2010) in order to be able to access healthcare on a fair basis. The flag sets out what those reasonable adjustments might be, along with any impairments the patient has as categorised by the Equality Act 2010, where the patient is happy to share this detail. The digital flag was piloted for people with a learning disability, but it can be used for everyone who falls within one of the groups of people covered by the Equality Act who might need a reasonable adjustment in their care.

In June 2020, NHS Digital published initial results from the Reasonable Adjustment Flag pilots, which took place in Gloucestershire and Devon between June 2019 and March 2020.

In the trial, staff securely created, accessed and updated the information on the NHS Spine using the Summary Care Record application (SCRa), a program designed to share key health information about patients to health and care staff with appropriate access rights. In the longer term, clinical and screening systems will be able to integrate with the capability so that more staff will be able to see it on their screens in their own systems when they search for the patient.

During the pilot, which took place in in various care settings including GP surgeries, hospitals and community services for learning disability, more than 70 flags were created by clinicians in conjunction with patients and carers. There were a wide range of adjustments identified, which could positively affect the experience and outcomes for patients and the experiences of carers and staff. Adding the Reasonable Adjustment Flag could also lead to other benefits, such as financial savings through reducing the number of missed appointments.

Now that the technology has been tested and feedback gathered through the initial pilot, further development and testing is taking place. It is expected the capability will be more widely available from the end of 2020.

Annual health checks

Annual health checks were introduced to try to minimise the health inequalities many people with a learning disability face. By identifying conditions such as diabetes or heart disease early or reducing people's risk of developing them in the first place, annual health checks can also help to reduce premature mortality and are therefore a vital part of the LeDeR response.

The NHS Long Term Plan set an ambition that by 2023/24 at least 75% of people aged 14+ with a learning disability will have an annual health check. In 2020/21 this is backed by increased investment for GP practices and primary care networks.

As part of the Quality Outcomes Framework for primary care (QOF), all GP practices are required to keep a register of patients with a learning disability. The benefits of being on the register for someone with a learning disability are clear – for people who are on the register GPs can offer proactive health screening for all aged 14 and over using the annual health check; proactively call them for a flu vaccination; and ensure that reasonable adjustments can be made to improve access to healthcare.

NHS England and NHS Improvement's guidance for general practice sets out how GPs should update their registers to ensure that eligible patients are flagged for a health check, with an additional £49m available to support improvements under the Quality Outcomes Framework (QOF) programme.

Find out more about QOF for supporting people with a learning disability.

Contact, a national voluntary sector organisation, is working with NHS England and NHS Improvement and the National Network of Parent Carers Forum to raise awareness of Annual Health Checks for young people aged 14 and over with GPs and parents. They have produced a factsheet explaining how parents can ensure that their young person is on the learning disability register and access an annual health check.

Contact have also co-produced two resources aimed at GPs and health professionals:

- Making GP practices more welcoming for disabled children and their families, outlines some of the barriers families can face accessing GP practices and includes useful suggestions for simple, reasonable adjustments that practices can make to reduce them.
- Health services for disabled children, gives an overview of some of the services disabled children might access.

There is a real drive to improve the uptake and quality of annual health checks in many local areas. For example, the practice manager for one GP practice in central Rochdale promotes annual health checks with patients, accompanying people to health screening appointments where necessary, resulting in good rates of screening for people on their learning disability register.

In Hertfordshire, commissioners are working with the looked after children team, disability nursing team, paediatricians, school nurses and parents of young people with a learning disability to raise awareness about the benefits of being added to the learning disability register and having an annual health check. In addition, a co-produced survey is being carried out by Healthwatch Hertfordshire to look at the quality of annual health checks and a report will be available later in the year.

ACE Anglia, a self-advocacy group in the East of England, has developed an annual health check peer educator network to increase the numbers of people with a learning disability attending their annual health check.

The network aims to educate people about keeping themselves healthy and explain how and why people should attend their annual health check. The education sessions run by ACE Anglia take the form of two-hour education sessions using films, worksheets, surveys and a chance have a go with the medical equipment that is used at an annual health check. The network also provides a series of resources to support people to attend their annual health check.

In 2019 389 people with a learning disability and 110 support staff attended one of 41 ACE Anglia face-to-face workshops and a further 14 had accessed the online version which was made available in July 2019. The ACE team also spread their message through events and conferences they attended.

Learning from reviews: GP learning disability registers

NHS North Lincolnshire, Rotherham Doncaster and South Humber Community Learning Disability Team has focused on identifying individuals eligible to be on the GP learning disability register to ensure they are offered and can access Annual Health Checks.

The team identified that people with a mild or moderate learning disability were being left off the register, because often these people were only known to social services. As a result, the primary care liaison nurse recommended that GP practices review their patient lists to identify who should be on their register but were not.

Supported by the CCG, the work has seen the number of people recorded on the practice register rise from 577 to 891 in the year, a significant improvement but still below the 2% (c.3,000 people) of the population estimated to have a learning disability. Similar work with children's services to identify individuals from the age of 14 who would benefit from annual health checks has resulted in an additional 24 young people being added.

The use of the GP register helps primary and community staff better monitor those at higher risk of illness and hospital admission and will enable reasonable adjustments to be made by the local A&E once they switch to a compatible computer system later this year.

Data driving better outcomes - why it is so important to capture information about people with a learning disability

It is essential that the treatment, outcomes and experiences of people with a learning disability can be understood and used to drive improvements in care. More is being done to capture and publish that data, including through national audits.

An example of this is the annual review of emergency laparotomies (the National Emergency Laparotomy Audit (NELA) (NELA, 2019)) This 'mainstream' survey of laparotomies has expanded its data collection to include collecting information on whether patients have a learning disability or autism. Audits like this when triangulated with data about presenting symptoms, intervention and outcomes will increase our system awareness and enable better care planning and provision.

Stopping over-medication of People with a Learning Disability (STOMP-STAMP)

Of the people with a learning disability whose deaths were reviewed by LeDeR in 2018, 19% were regularly taking antipsychotic medication at the time of their death and 27% of this group were taking more than one type of antipsychotic.

While this medication may be right for some people, antipsychotics can cause serious health problems if taken at too high a dose, for too long, or given for the wrong reasons. They may interact with some other common medications. NHS England and NHS Improvement's programme dedicated to stopping overmedication in people with a learning disability of all ages is called STOMP-STAMP.

As well as raising awareness of the risks of overmedication, STOMP-STAMP is helping to embed the role of the new clinical pharmacists in primary care networks. These roles will help increase overall capacity and improve care and safety through measures such as medication reviews for high-risk patients, including some with a learning disability.

The GP contract includes the requirement for a 'structured medication review' to be undertaken. Thousands of clinical pharmacists are being deployed across Primary Care Networks to support this requirement. Additional clinical pharmacists in general practice will complement, not replace, specialist pharmacy support for people with a learning disability and will liaise with those services to ensure joined-up care for this vulnerable patient group. These pharmacists will undergo an additional 18 months training which includes the needs of patients with a learning disability. We will continue to work with pharmacy colleagues to ensure the needs of people with a learning disability are embedded across the system.

Partnership working

This year, the Voluntary Organisations Disability Group (VODG) hosted three conferences for social care providers to share learning and spread best practice in partnership with NHS England and NHS Improvement. The events included contributions from social care providers, people with a learning disability, family members, NHS England and NHS Improvement with other system partners.

More than 200 delegates came to Leeds, London and Birmingham to hear about the core themes and actions from LeDeR and to discuss how better partnership working across health and social care can improve outcomes and experience. Feedback from the events will inform work in the coming year and further information, including links to the presentations, can be found here:

- Leading for better health
- Learning from LeDeR
- Staying healthy.

The Mental Capacity Act

A consistent theme emerging from reviews is the need for more understanding of, and adherence to the Mental Capacity Act (MCA) 2005 across both health and social care. The MCA is clear that everyone should be assumed to have capacity to make decisions about their life unless proven otherwise. If someone is unable to make a decision, then every effort should be made to involve the person in the decision so it can be made in their best interests. This includes making reasonable adjustments.

LeDeR reviews have identified that across all services, including social care, there are issues with the application of the act and the roles and responsibilities of individuals involved in the person's care, both in day-to-day care provision and longer-term care and support planning. The third of the series of three events in partnership with VODG focused on 'Staying Healthy' and was aimed at frontline social care staff. A session was held to explore the dilemmas providers face around individual choice, capacity, service models and organisational culture.

NHS England and NHS Improvement have been co-producing with experts by experience some new resources on the Mental Capacity Act for people with a learning disability, their families and carers and professionals. However, we have had to pause this work due to the COVID-19 response. Further work on the Mental Capacity Act will be a focus of our work in the year ahead.

The MCA, the role of Independent Mental Capacity Advocates (IMCAs) and understanding and recording consent and best interest decisions were areas of concern identified from LeDeR reviews in Derbyshire. In response, the local LeDeR steering group have developed a training course for all Derbyshire health and social care providers. This ran five times in January 2020 to give attendees:

- an awareness of the legal principles of the MCA and how they work in practice
- confidence in using the legislation to assess mental capacity and determine best interests, and documenting the same
- an understanding of the difference between restricting movement and depriving liberty
- an ability to identify which legal procedure is required to authorise a deprivation of liberty
- and a better understanding of when and how to access the Court of Protection.

In total, 141 people from the NHS, social care, the voluntary sector and private providers attended the training in January. Feedback was positive and most said they were confident they would be able to apply what they had learned. Further training sessions are now planned.

NHS England and NHS Improvement's response to the University of Bristol LeDeR annual report 2019 (published 2020)

The NHS continues to demonstrate its commitment, set out in the NHS Long Term Plan 2019, to address the premature mortality and health inequalities of people with a learning disability.

The clear expectations of CCGs to complete LeDeR reviews in a timely way set out in the NHS Operational Planning and Contracting guidance for 2019/20 has led to some progress.

More LeDeR reviews than ever were completed in 2019, and as of the end of March 2020, 63% of eligible reviews (not otherwise subject to statutory investigations or reviews or on hold to enable families to take part) had been completed within six months of notification. However, there is more work to do to support CCGs to complete 100% of eligible reviews within six months by December 2020 (i.e. reviews which are not subject to other statutory processes).

We have put details of what we are planning in the year ahead in response to the university of Bristol recommendations in Appendix 4.

In addition, there are some key actions we will be taking in the next 12 months:

- We will work closely with people with a learning disability, families, the voluntary and independent sector, local government and health to design our long-term approach to LeDeR.
- We will work with partners to develop the LeDeR review system so that the web-based platform provides more timely access to data and learning to inform continuous planning and service improvement
- We will increase dedicated clinician time to support LeDeR Action from Learning and work with the national clinical directors across the NHS to address the clinical findings of the 2019 report.

We will continue to work with senior pharmacists across the system to strengthen our commitments and approaches to reviewing medication for people with a learning disability including medication reviews with pharmacists trained to understand the needs of people with a learning disability.

Appendix 1: Response to recommendations from the University of Bristol 2018 report

This table only includes recommendations from the 2018 report which relate to NHS England and NHS Improvement. Links to responses to recommendations from other organisations can be found in the helpful resources document.

Year	Recommendation from the University of Bristol	Response from NHS England and NHS Improvement
2018/19	Consider designating national leads within NHS England and local authority social care to continue active centralised oversight of the LeDeR programme.	There is dedicated resource, leadership and oversight of the LeDeR programme at national and regional level in NHS England and NHS Improvement and within all Clinical Commissioning Groups. National capacity has been increased in the past year to help provide additional oversight of the LeDeR programme including oversight of local delivery.
2018/19	NHS England to support Clinical Commissioning Groups to ensure the timely completion of mortality reviews to the recognised standard.	£5 million in funding was provided to support organisations to complete LeDeR reviews and to apply their findings. North East Commissioning Support Unit (NECS) was commissioned by NHS England and NHS Improvement to carry out reviews of older cases and funding was made available to support CCGs to develop sustainable review systems By the end of 2020, all CCGs are expected to complete reviews within six months of a notification of a death as standard (except where other investigatory processes may require a longer timescale).
2018/19	Clinical Commissioning Groups and local LeDeR steering groups to use local population demographic data to compare trends within the population of people with learning disabilities. They should be able to evidence whether the number of deaths of people from Black, Asian and Minority Ethnic groups notified to LeDeR are representative of that area and use the findings to take appropriate action.	The 2019/20 NHS Operational planning and contracting guidance for CCGs requires that each CCG develops and maintains an action plan to address learning from reviews and publish an annual report. We would expect these to identify and address inequalities within their local population.

Year	Recommendation from the University of Bristol	Response and update
2018/19	The Department of Health and Social Care and NHS England to support national mortality review programmes to work with 'Ask, Listen, Do' and jointly develop and share guidelines that provide a routine opportunity for any family to raise any concerns about their relative's death.	Resources on Ask, Listen, Do have been developed by NHS England and NHS Improvement and delivered in partnership with health and social care partners. The LeDeR programme will work with Ask Listen Do to incorporate the principles into future work around the design of the LeDeR programme.
2018/19	The Department of Health and Social Care, working with a range of agencies and people with learning disabilities and their families, to prioritise programmes of work to address key themes emerging from the LeDeR programme as potentially avoidable causes of death. The recommended priorities for 2019 include: i) recognising deteriorating health or early signs of illness in people with learning disabilities and ii) minimising the risks of pneumonia and aspiration pneumonia.	The cross-system Sepsis Board continues to focus on people with a learning disability including work to explore the use of a digital flag for learning disability on sepsis data sets. Easy Read material on sepsis has also been developed. We have commissioned an evaluation of NEWS2 and Restore2™ to ensure there is a robust evidence base for their roll out or adaptation to meet the needs of people with a learning disability and autistic people. NHS England and NHS Improvement worked with Public Health England to ensure reasonable adjustments are made to allow people to access flu vaccination with supporting materials provided through the annual flu campaign. NHS England and NHS Improvement are working with the British Thoracic society to produce clinical standards and an ideal pathway of care for pneumonia in adults with a learning disability. This will include a broader statement on aspiration pneumonia which will be particularly relevant to those with a learning disability.

Year	Recommendation from the University of Bristol	Response and update
2018/19	The Department of Health and Social Care, working with a range of agencies and the Royal Colleges to issue guidance for doctors that learning disabilities should never be an acceptable rationale for a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order, or to be described as the underlying or only cause of death on Part I of the Medical Certificate Cause of Death.	In May 2019, Professor Stephen Powis, National Medical Director for NHS England and NHS Improvement, wrote to the NHS system reminding staff that learning disabilities should never be used as a cause of death or rationale for a DNACPR recommendation. The 2019 report indicates a reduction in the use of DNACPR in those reviews considered as part of that report.
2018/19	Medical examiners to be asked to raise and discuss with clinicians any instances of unconscious bias they or families identify, eg in recording learning disabilities as the rationale for DNACPR orders or where it is described as the cause of death	NHS England and NHS Improvement instigated the use of medical examiners in acute trusts during 2019/20, and while the coronavirus pandemic interrupted progress, trusts are expected to resume implementation soon. More than 500 senior doctors have completed medical examiner training, which provides extensive guidance on awareness of the risks of bias and the importance of independent scrutiny of causes of death. Guidance for doctors completing medical certificates of causes of death notes that "learning disabilities…are rarely sufficient medical explanation of the death in themselves".

Appendix 2: Update on actions by NHS England and NHS Improvement

The following actions that NHS England and NHS Improvement have committed to as part of the LeDeR programme. This table shows progress made towards these actions in 2109/20.

Theme	Agreed action	Update for 2019/20
Cancer	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.	Cancer screening programmes are led by Public Health England who have developed in partnership with NHS England and NHS Improvement, a range of documents to make cancer screening more accessible. NHS England and NHS Improvement is talking with cancer alliances about ensuring access to screening for people with a learning disability. Locally there are many examples of screening services making reasonable adjustments to allow people with a learning disability equal access to screening.
Cancer	NHS England and NHS Improvement will continue to work with Public Health England (PHE) to ensure that all screening programmes are designed to support a narrowing of health inequalities and that this is reflected within provider contracts	Public Health England (PHE)is developing a repository of good practice on screening programmes. Health inequalities is an existing requirement of the NHS provider contract for screening services. The learning disability improvement standards[1] apply to all providers including those who provide screening services.
Cancer	NHS England and NHS Improvement Public Health Commissioning Team are continuing to work with PHE to implement the PHE Screening Inequalities Strategy.	PHE is collecting examples of best practice and exploring the development of a screening e-learning resource aimed specifically at carers. PHE is arranging a national PHE Screening Inequalities conference, with access for people with a learning disability as the key theme (planning has been interrupted by COVID-19).

[1] https://improvement.nhs.uk/resources/learning-disability-improvement-standards-nhs-trusts/

Theme	Agreed action	Update for 2019/20
Cancer	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.	This work remains an ongoing feature of the cancer programme across England led by local cancer alliances.
Cancer	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.	The reasonable adjustments digital flag pilot has been completed with plans for further roll-out later in 2020. Roll out plans may be impacted by COVID-19.
Constipation	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.	The Books Beyond Words constipation resource was officially launched in 2019/20. A constipation campaign has been commissioned but plans to deliver it over the summer of 2020 have been revised because of COVID-19.

Theme	Agreed action	Update for 2019/20
Sepsis	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.	The cross-system sepsis board is now part of the patient safety strategy in NHS England and NHS Improvement. The care of people with a learning disability is an area of action for the strategy.
Sepsis	Continue to raise awareness of sepsis among healthcare workers including community pharmacy, health visitors, care home workers, including a focus on learning disability.	NHS England and NHS Improvement have developed easy read resources on sepsis, which are available online here. We have supported HEE with the dissemination of free online training.
Sepsis	Develop a surgical sepsis dashboard that identifies people on surgical wards and via A&E, explore the potential for flagging people with a learning disability within this.	NHS England and NHS Improvement has commissioned an evaluation of NEWS2 and Restore2™ to determine their suitability to identify people who have a learning disability and flag what reasonable adjustments they might need. The development of the surgical dashboard has been interrupted by the COVID-19 pandemic.
Respiratory	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.	GPs provide flu vaccination under a Directed Enhanced Service (DES). The specification for flu vaccination clearly states that 'Clinicians should offer immunisation to all patients with a learning disability'.

Theme	Agreed action	Update for 2019/20
Respiratory	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.	A flu campaign was planned and implemented and the impact will be measurable in the PHE data being published later in the year. Several areas of the country have run their own local campaigns to increase take up of vaccination for people with a learning disability and their families and carers.
Respiratory	NHS England and NHS Improvement to consider whether family carers should also be eligible for flu vaccinations.	Family carers are eligible for vaccination as part of the national flu campaign.
Respiratory	The NHS England and NHS Improvement cardiovascular 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.	Work has been commissioned from the British Thoracic society to produce clinical standards and an ideal pathway of care for pneumonia in adults with a learning disability. This will include a broader statement on aspiration pneumonia which will be particularly relevant to those with a learning disability. This work is ongoing because of COVID-19 and remains an action for the CVD programme.

Theme	Agreed action	Update for 2019/20
Medication	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.	Primary care networks (PCNs) are now established across the country. With a patient population of around 30 - 50,000 they provide comprehensive primary care services. Numbers of clinical pharmacists will be expanded and, by 2023/24, a typical PCN of 50,000 patients could choose to have its own team of approximately six whole-time-equivalent (WTE) clinical pharmacists. The staffing in each PCN is the decision of that local PNC in agreement with its CCG. This briefing helps to explain the pharmacist and primary care network role.
Medication	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.	As above.

Theme	Agreed action	Update for 2019/20
DNA CPR and Cause of Death	Letter from Steve Powys to 'system' re DNACPR/ Cause of death (complete).	A letter was sent out by Professor Stephen Powis in May 2019. It has since been followed up with further advice around DNACPR endorsed by partner organisations.
Annual Health Checks (AHCs)	The NHS 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 making it easier for annual health checks to be done, and done well.	GP practices are paid to carry out AHCs for people with a learning disability in their practice population through a directed enhanced service (DES) and, as part of this record, reasonable adjustments required by patients in accessing healthcare. Targeted plans to increase the uptake of checks were due to start in April 2020 but have been delayed by COVID-19. We will be focusing on this as part of the Help us, Help you campaign. This campaign has been launched by NHS England and NHS Improvement as part of phase 2 of our response to COVID-19 in order to restore critical health services Annual health check data is published by NHS Digital on a quarterly basis (https://digital.nhs.uk/data-and-information/publications/statistical/learning-disabilities-health-check-scheme).
Creating momentum in the system to affect service improve-ments	Social care / independent organisation commissioned to host three events to talk about how to improve health services.	Three events were hosted by Voluntary Organisations Disability Group (VODG). Write ups from all three events can be found here: 1. www.vodg.org.uk/event-roundups/staying-healthy-event-roundup 2. www.vodg.org.uk/event-roundups/learning-from-leder-event-roundup 3. www.vodg.org.uk/news/leading-for-better-health-event-roundup

Appendix 3: Annual reports from LeDeR local areas

Every CCG was asked via the NHS Operational and Planning Contracting Guidance 19/20 to publish an annual report which demonstrates their local action from learning. At the time of writing the annual reports from some local areas have not been published due to the impact of the COVID-19 pandemic. Those CCGs have committed to publishing by the end of September 2020.

CCGs work collaboratively in a LeDeR steering group and some CCGs have therefore published a steering group annual report. Some CCGs have chosen to publish their reports across their transforming care partnership (TCP) or integrated care system (ICS).

The following CCGs have published their annual LeDeR reports. LeDeR Steering Group/CCG[2]/ICS[3]/TCP[4]	Link to annual report
Arden LeDeR Steering Group*: • NHS Coventry and Rugby CCG • NHS Warwickshire North CCG • NHS South Warwickshire CCG *This report presents information about the deaths of people with a learning disability aged 4 years and over notified to the LeDeR programme from its commencement on 1st October 2017 to 31st March 2019.	**Arden**
Birmingham and Solihull LeDeR Steering Group: • NHS Birmingham and Solihull CCG *This report covers the calendar year from January 2019 to December 2019.	**Birmingham and Solihull**
NHS Heywood, Middleton and Rochdale CCG *This report covers the work done in 2018/2019.	**Heywood, Middleton and Rochdale**
Lincolnshire LeDeR Steering Group: • NHS Lincolnshire East CCG • Lincolnshire East CCG • South Lincolnshire CCG *This report covers the period January 2019 to January 2020.	**Lincolnshire**

[2]CCG = Clinical Commissioning Group [3]ICS = Integrated Care System
[4]TCP = Transforming Care Partnership

The following CCGs have published their annual LeDeR reports. LeDeR Steering Group/CCG[2]/ICS[3]/TCP[4]	Link to annual report
• NHS Merton CCG and NHS Wandsworth CCG *This report covers the period from the beginning of the LeDeR programme in mid-2017 to 31st March 2019.	Wandsworth
North Cumbria LeDeR Steering Group: • NHS North Cumbria CCG *This report covers the period from April 2018 to March 2019.	North Cumbria
• NHS St Helens CCG *This report covers the period from the beginning of the LeDeR programme in 2017 to the end of March 2020.	St Helens
BANES, Wiltshire & Swindon LeDeR Steering Group: • NHS Bath and North East Somerset CCG • NHS Swindon CCG • NHS Wiltshire CCG *This report covers the calendar year January 2019 to December 2019.	Bath and North East Somerset, Swindon and Wiltshire
BRISTOL AND NSSG LeDeR Steering Group: • Bristol, North Somerset and South Gloucestershire CCG *This report covers the calendar year January 2019 to December 2019.	Bristol, North Somerset and South Gloucestershire
Gloucestershire LeDeR Steering Group: • NHS Gloucestershire CCG *This report covers the work done in Gloucestershire in 2018/2019.	Gloucestershire

The following CCGs have published their annual LeDeR reports. LeDeR Steering Group/CCG[2]/ICS[3]/TCP[4]	Link to annual report
Somerset LeDeR Steering Group*: • NHS Somerset CCG *This report presents information about the death of people with learning disabilities in Somerset aged 4 and over notified to the LeDeR programme from 1 July 2017 to 31 December 2019 with particular focus on activities during 2019.	Somerset
Nottinghamshire LeDeR Steering Group: • NHS Mansfield and Ashfield CCG • NHS Nottingham City CCG • NHS Rushcliffe CCG *This report covers the period 2017-2019.	Nottinghamshire
Suffolk LeDeR steering Group*: • NHS Ipswich and East Suffolk CCG • NHS West Suffolk CCG *This report covers the work done in Suffolk in 2018/2019.	Suffolk
Essex LeDeR Steering Group*: • NHS Basildon & Brentwood CCG • NHS Castle Point & Rochford CCG • NHS Mid Essex CCG • NHS North East Essex CCG • NHS Southend CCG • NHS Thurrock CCG • NHS West Essex CCG *This report covers the work done in Essex in 2018/2019.	Essex

The following CCGs have published their annual LeDeR reports. LeDeR Steering Group/CCG[2]/ICS[3]/TCP[4]	Link to annual report
Hertfordshire LeDeR Steering Group*: • NHS East and North Hertfordshire CCG • NHS Herts Valleys CCG *This report covers the work done in Hertfordshire in 2018/2019.	Hertfordshire
Norfolk LeDeR Steering Group*: • NHS Norfolk and Waveney CCG *This report covers work done in Norfolk in 2018/2019.	Norfolk
Berkshire East LeDeR Steering Group: • NHS East Berkshire CCG *This report covers work done in 2018/2019.	East Berkshire
• NHS Bassetlaw CCG *This report covers work done during 2019/20.	Bassetlaw
Staffordshire and Stoke on Trent CCGS: • NHS Cannock Chase CCG • NHS East Staffordshire CCG • NHS North Staffordshire CCG • NHS South East Staffordshire and Seisdon Peninsula CCG • NHS Stafford and Surrounds CCG • NHS Stoke-on-Trent CCG *This report covers work done during 2019/20.	Staffordshire and Stoke on Trent

Appendix 4: Action plan in response to University of Bristol Annual Report 2019 (published 2020)

	Recommendation	Audience	NHS England and NHS Improvement Actions
1	A continued focus on the death of all adults and children from BAME groups is required.	NHS England and NHS Improvement, Department for Health and Social Care.	LeDeR steering groups to be asked to identify a BAME lead. We will explore the inclusion of the needs of people with a learning disability from BAME communities in the revised NHS Equality Delivery System.
2	For the Department of Health and Social Care (DHSC) to work with the Chief Coroner to identify the proportion of deaths of people with a learning disability (and possibly other protected characteristics) referred to a Coroner in England and Wales.	Department of Health and Social Care.	
3	(Repeated form the House of Lords Select Committee on the Mental Capacity Act 2005). The standards against which the Care Quality Commission inspects should explicitly incorporate compliance with the Mental Capacity Act as a core requirement that must be met by all health and social care providers.	Department for Health and Social Care and Care Quality Commission.	

	Recommendation	Audience	NHS England and NHS Improvement Actions
4	Consider the recommendations from the 'Best Practice in Care Coordination for people with a learning disability and long term conditions' (March 2019) report and; • Establish and agree a programme of work to implement the recommendations • Liaise with NIHR regarding the importance of commissioning a programme of work that develops, pilots and evaluates different models of care coordination for people with learning disabilities.	Department for Health and Social Care and National Institute for Health Research.	
5	Adapt the National Early Warning Score 2 regionally, such as the Restore2™ in Wessex, to ensure it captures baseline and soft signs of acute deterioration in physical health for people with learning disabilities by: • Involving people with learning disabilities, their families and professional organisations • Disseminating for use across acute, primary and community settings.	NHS England and NHS Improvement, professional organisations and people with a learning disability.	We will evaluate the use of NEWS2 and Restore2™ and other early warning approaches to ensure that they meet the needs of people who have a learning disability and adapt documentation to meet any changes required. We will implement at least one pilot programme using Restore2™, virtual wards and oximeters to support care staff to identify early signs of deterioration. We will train 5,000 paid and unpaid carers in the use of Restore2™ mini to help them to detect early signs of deterioration.

	Recommendation	Audience	NHS England and NHS Improvement Actions
6	Consider develop, piloting and introducing: • Specialist physicians for people with learning disabilities, their families and professional organisations • A Diploma in Learning Disabilities Medicine • Making learning disabilities' a physician speciality of the Royal College of Physicians.	Department for Health and Social Care, Royal College of Physicians.	
7	Consider the need for timely, NICE evidence-based guidance that is inclusive of prevention, diagnosis and management of aspiration pneumonia in adults and children. The outcome of such consideration should be shared with DHSC and NHSE.	Department for Health and Social Care, National Institute for Clinical Excellence, NHS England and NHS Improvement.	We have commissioned a toolkit and guidance from British Thoracic Society around bacterial and aspiration pneumonia.
8	RightCare to provide a set of resources to support systems to improve patient outcomes for adults and children at risk of aspiration pneumonia	NHS England and NHS Improvement.	This work is already in progress and will be published this year.

	Recommendation	Audience	NHS England and NHS Improvement Actions
9	Safety of people with epilepsy to be prioritised. The forthcoming revision of the NICE guidelines 'Epilepsies in children, young people and adults' to include guidance on the safety of people with epilepsy, and safety measures to be verified in Care Quality Commission inspections.	Department of Health and Social Care, Care Quality Commission.	
10	For a national clinical audit of people admitted to hospital for a condition related to chronic constipation. The National Clinical Audit and Patient Outcomes Programme is one way this could happen.	NHS England and NHS Improvement.	We will actively work across the system to find the most appropriate route to understand the prevalence, causes and consequences of chronic constipation.

In addition to the specific recommendations in the 2019 report, we continue to be concerned about the overuse of medication for people with a learning disability including but not limited to the use of anti-psychotics. We will therefore work with pharmacists and leaders across the system in the coming year to take action to improve prescribing practice and medicine reviews for people with a learning disability.

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