

Learning disability
mortality review
(LeDeR):

**Action from
learning report
2020/21**

Contents

Acknowledgements	3
Foreword	4
What will you find in this report?	6
Co-production and family involvement	7
Spotlight on... Reasonable adjustments	8
COVID-19	11
Covid Vaccination Programme	13
Adapting in lockdown	15
Action from learning in 2020/21: Management of medical conditions	17
Respiratory conditions	17
Seasonal flu vaccination	19
Cardiac care	21
Identifying deterioration/sepsis	22
Diabetes	27
Constipation	27
Cancer	30
Epilepsy	34
Action from learning in 2020/21: Changing how we work	36
DNACPR – Do Not Attempt Cardio Pulmonary Resuscitation	36
End of life care	37
Reasonable adjustments	39
Annual health checks (AHCS)	40
STOMP-STAMP (medication)	42
Inequalities for people from minority ethnic communities	44
Terms used	46
Appendix 1: Update on actions by NHS England and NHS Improvement	48
Appendix 2: COVID-19 response - Progress on commitments	52
Appendix 3: Recommendations from the 2020 University of Bristol LeDeR report and our proposed actions in response to them	55

An [easy read version of this document](#) is available and other alternative formats are available on request.

Acknowledgements

We would like to express our gratitude to the family members, health and care staff and many others who have contributed to a LeDeR review into the life and death of a loved one or someone in their care. Families have shared their stories for inclusion in this report and organisations their actions to improve services, based on the learning from local LeDeR reviews.

We thank the team at the University of Bristol for their hard work and commitment over the past six years in establishing and taking LeDeR forward to help people with a learning disability live longer, healthier lives, and especially Professor Pauline Heslop.

Finally, we are grateful to the LeDeR workforce across England who have completed LeDeR reviews and driven work to improve the lives of people with a learning disability during the COVID-19 pandemic.

Foreword

This year many staff, including those involved in LeDeR across the country and in our national LeDeR team, were redeployed to support the response to the COVID-19 pandemic. Despite this, the LeDeR increased the percentage of eligible reviews¹ completed within six months from 64% in March 2020 to 97% by March 2021. We also published a new [LeDeR policy](#) in March 2021.

This gives a significant emphasis to ensuring that actions are delivered locally in response to learning from reviews, so that we can be assured that LeDeR is making a positive difference to the lives of people with a learning disability and their families across England.

[The NHS Long Term Plan](#) made a commitment to continue LeDeR and to improve the health and wellbeing of people with a learning disability. This report identifies some of the work across the NHS in the past year to address the findings from LeDeR reviews, improve care and prevent premature mortality. With 42 LeDeR steering groups across England reviewing deaths and taking actions to improve services, we cannot describe everything that is being done, but we give an idea of the scope and scale of the improvements being made thanks to the learning from LeDeR reviews; learning that is greatly aided by the contribution of families and carers of people who have died.

Most importantly, LeDeR is a service improvement programme to ensure that local services can learn and action changes to enable people with a learning disability in their area to live longer, healthier lives. The University of Bristol annual LeDeR report provides an analysis of the learning from all reviews and recommends national actions for NHS England and NHS Improvement and our partners.

This year's University of Bristol annual LeDeR report does show some early indicators of improvements in the care of people with a learning disability; however, there is much more work to be done to ensure that these improvements are felt across all aspects of service provision and for all people with a learning disability. We have already funded programmes of work to better understand and address some of the inequalities highlighted this year, including work with Learning Disability England and the Race Equality Foundation to strengthen support available to people with a learning disability from minority ethnic communities and their families.

Our new [LeDeR policy](#) includes a requirement to undertake a focused LeDeR review of the care of people from minority ethnic communities and, in response to this year's annual report, we are introducing a requirement for a focused review for people who died within five years of being subject to mental health or criminal justice

¹ Eligible reviews are those that are over six months old and due to have been completed. Notifications of deaths of children under 18 are not included as CCGs are not responsible for the completion of reviews of child deaths. These fall under the Child Death Review Programme. 'On hold' notifications are not included where the family have requested a delay or the CCG cannot proceed with the review due to ongoing coronial or other legal processes.

restrictions. Later in 2021 we will begin LeDeR reviews for autistic people who do not have a learning disability, which offers an important opportunity to tackle the health inequalities faced by this group of people.

Many people with a learning disability may face additional risks from COVID-19, particularly if they have multiple underlying health conditions. The [COVID-19 LeDeR review](#) published in November 2020 gave helpful insights into COVID-19 deaths among people with a learning disability and our [COVID-19 Action from Learning report](#) and the appendices of this report give details of the actions we have taken to improve care. While the pandemic has highlighted vulnerabilities and inequalities for many different groups, it has provided opportunities to work together across systems and programmes to improve care and influence change in ways that will leave a lasting impact.

Some of our proposed actions to tackle health inequalities have inevitably been delayed this year. For example, our respiratory medicine experts were occupied with frontline patient care. Work to improve respiratory health has now restarted and will continue at pace throughout the year.

Everyone reading this report, whatever role or organisation they are in, can play a part in improving healthcare for people with a learning disability and in identifying and promoting high quality, person-centred care and reasonable adjustments. We encourage you to use this report to consider how you, your organisation, your family, your charity or your healthcare practice can continue to help us drive that change.



Claire Murdoch, National Director of Mental Health, Learning Disability and Autism



Roger Banks, National Clinical Director, Learning Disability and Autism



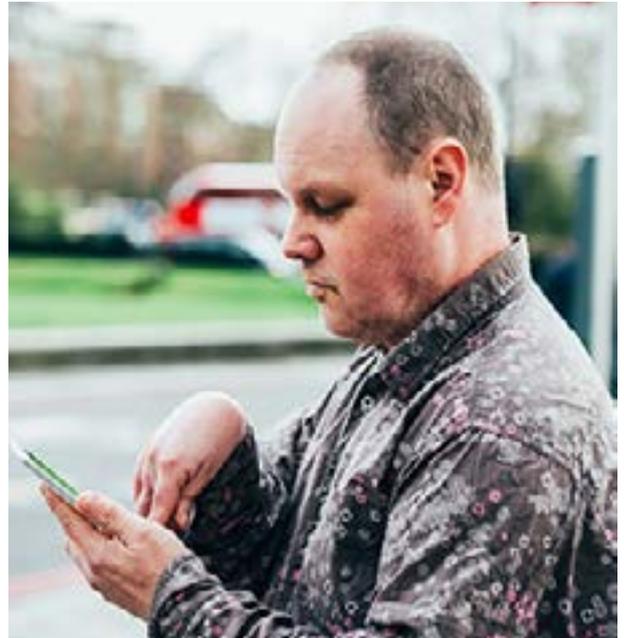
Ted Goodman, Family Carer Advisor, Learning Disability and Autism Programme

What you will find in this report

The fifth annual University of Bristol LeDeR report considers reviews of deaths notified to LeDeR in the calendar years 2018 to 2020, summarises what is working well and makes recommendations to address inequalities and prevent premature mortality among people with a learning disability.

This action from learning report highlights some of the many activities and measures health and social care services have put in place since our last report in July 2020, both locally and nationally. It also updates the commitments that we made in both that report and the [COVID-19 action from learning report](#), published in November 2020.

The accompanying [helpful resources](#) document details updates from government and arm's length organisations, useful guidance, data and other materials mentioned in this report.



Co-production and family involvement

Co-production and working with people with lived experience are at the heart of the Learning Disability and Autism programme and LeDeR. Our national team includes people with a learning disability, autistic people, family carers and bereaved family carers, to ensure that every aspect of our work is directly informed by people whose lives are affected by LeDeR. LeDeR also has an independent advisory group which includes representation from people with a learning disability and family carers.

We consult widely with these groups, self-advocacy groups, commissioners, health and care providers, social care providers, voluntary sector organisations and LeDeR experts (academics and policy experts). They have informed the design of our long-term approach to LeDeR and the development of a new [LeDeR policy](#) that is fit for the future.

More than 400 views were shared with us. Two voluntary sector organisations – [Inclusion North](#) and [Bemix](#) – asked people with lived experience for their thoughts on the future of LeDeR. Inclusion North talked to its ‘Stop People with a Learning Disability Dying Too Young’ group while Bemix surveyed its members. Others took part in independent research undertaken on our behalf by IPSOS Mori.



The new LeDeR policy re-emphasises the importance of involving bereaved family members or someone who knew the person well throughout the LeDeR process and makes clear the expectation that communication with families is timely, authentic and sensitive. We recognise what a difficult time it is for bereaved carers, who provide such a rich contribution in building a picture of the person who has died and describing their experience of care.

Spotlight on... reasonable adjustments

Providing care that is accessible for everyone including people with a learning disability is a priority for the NHS and the learning disability stakeholder organisations we work with. These are a few examples of the 'reasonable adjustments' made locally to ensure people with a learning disability – and where relevant their carers – were offered vaccinations.

Partnership in action

In Kingston, South West London, the community learning disability team, learning disability nurses and staff from [Mencap's Searchlight Centre](#) joined forces to deliver an afternoon flu vaccination clinic at the centre, a setting more familiar to people with a learning disability, in November 2020.

A community pharmacist gave vaccinations to people with a learning disability, their families and carers, and everyone who attended was given local health information in an easy read format.



"I was quite anxious about having the flu vaccine but going to the Searchlight Centre where I know people made me feel better about having it. They let mum come into the room with me which also helped."

Jack, who regularly attends Mencap's Searchlight Centre in Kingston, South West London.

Increasing uptake of flu vaccinations

We commissioned Contact, the national charity for families with disabled children, who worked with the [National Network of Parent Carer Forums](#) and 80 members of the [Disabled Children's Partnership \(DCP\)](#), to increase the uptake of flu vaccines by disabled young people and their carers between September and December 2020.

Contact's social media campaign reached 51,795 people and 21,000 readers of its weekly What's New newsletter with [questions and answers about getting the flu vaccine](#), and local newspapers – from the Dorset Echo to the Wirral Observer – accepted 56 Contact articles and letters to the editor encouraging parent carers to be vaccinated too.

Contact co-produced a podcast for parent carers of disabled children. This featured [mum Rosie talking about the reasonable adjustments](#) her son Blake needs to receive a flu vaccination, as well as tips for parents on what to do if their child needs extra support.

Vaccination in a relaxed setting

In February 2021, South East London CCG and Lewisham Primary Care Network (PCN) established two sites to deliver COVID-19 vaccinations in a relaxed environment for 110 people living in care homes for people with mental health difficulties or a learning disability.

The PCN provided information on vaccination and consent forms in easy read format in advance, appointments were lengthened, and staff were available to communicate with residents in Makaton – symbols, signs and speech – where this was helpful. Refreshments helped put everyone at ease while they waited.

The teams used the post-vaccine waiting time to deliver health checks that could not be delivered remotely, including blood pressure monitoring. The results were then shared with GPs for completing annual health checks (AHCs).

“One resident signed to me that he wanted to see his sister who he hasn’t been able to see for a year. Each vaccination brought people’s desires closer to being a reality. I felt very fortunate to be part of such an organised vaccination set up and also to be able to support the vaccination of people with a learning disability and their carers who are so vulnerable to COVID-19.”

Anna Crossley, Professional Lead for Acute and Emergency Care, Royal College of Nursing, and volunteer vaccinator.



Olu with her daughter Christiana - who both received information from Contact about getting a flu vaccine

COVID-19

Families, carers and people working in health and social care have been proactive in trying to protect the people they support from the risks of COVID-19. However, many people with a learning disability live with health conditions which may put them at greater risk, and the pandemic has emphasised gaps in health equality.

Since May 2020 we have published the [number of deaths notified to LeDeR](#) of people with a learning disability after contracting COVID-19 (confirmed and suspected).

We have learned a lot through this year about how COVID-19 affects people with a learning disability and how to protect vulnerable communities from the virus. We have taken prompt actions and issued guidance in response to this learning to help prevent deaths in any subsequent waves of the virus.

Public Health England (PHE) [published its review](#) of the deaths of people with a learning disability from COVID-19 and the [University of Bristol published a report](#) reviewing 206 deaths of people notified to LeDeR at the start of the pandemic and the learning from the analysis of those deaths.

Our COVID-19 [action from learning report](#) (published November 2020) set out our commitments to learn from the COVID-19 LeDeR review and implement the changes to services required.

To strengthen awareness and mobilise action we presented our learning and the University of Bristol COVID-19 report to:

- NHS England and NHS Improvement
- Regional medical directors
- National Incident Response Board
- Regional heads of learning disability and autism
- Mental health and learning disability trust chief executives
- GPs.

Progress against these commitments includes:

- Clinical commissioning groups (CCGs) have created '[virtual wards](#)' to monitor patients with a learning disability and other people with COVID-19 at risk of deteriorating at home or in care homes.
- By the end of May 2021, more than 7,000 carers have been trained in [Restore 2™ mini](#), to help them detect the early signs of deterioration in a person they are supporting and to communicate these to healthcare staff, including GPs.
- In summer 2020, we asked GP practices, via the Quality and Outcomes Framework, to review all DNACPRs (a decision not to attempt resuscitation) for people with a learning disability registered with their practice and to confirm that they were determined appropriately and remain clinically appropriate. This requirement has been included in the [primary care/GP contract for 2020-21](#).

- We are working to maximise the accessibility of NHS 111's telephone service for people who are autistic or have a learning disability and to ensure the accessibility of NHS 111 online.
- Published an [easy read 111 first leaflet](#) and shared this with stakeholder networks, to make sure that people with a learning disability and autistic people are aware of this new service and to remind them of their right to ask for reasonable adjustments.
- Used our regular monthly GP webinars to help GPs improve their registers of who should be considered at higher risk of serious illness from COVID-19 and remind them of the risks of 'diagnostic overshadowing' – that is, assuming someone's symptoms or behaviour are due to their learning disability – and the need to make reasonable adjustments.
- 'Grab and Go Guide' – a [COVID-19 specific short hospital passport](#) for people to use instead of their usual hospital passport in urgent situations related to COVID-19, co-produced with people with a learning disability and stakeholders, and shared across the NHS and with stakeholders.
- Published a [clinical guide for NHS frontline staff](#) on how to communicate with a person with a learning disability who attends hospital without the support of a carer or a learning disability liaison nurse.
- Gave regular guidance to the NHS throughout the pandemic, and in the run up to the national vaccination programme, to ensure that the needs of people with a learning disability and/or people who are autistic continue to be appropriately considered. For example, we reminded colleagues across the NHS of the need to make 'reasonable adjustments' and highlighted the role staff with particular experience and expertise in learning disability and health liaison can play, e.g. learning disability nurses can ensure frontline clinicians and vaccinators understand reasonable adjustment needs.

For more detail, please see the appendices.

These two examples illustrate what regions have done to reduce the risks of COVID-19.

Rapid learning to protect people

At the start of the pandemic the London learning disability and autism team worked with local CCGs to develop a COVID-19 'rapid review' tool and used this to review 77 deaths and identify any themes for learning to keep people safe, such as improving local support or escalating concerns. This learning was quickly shared across the system to effect change.

The North West region used a similar approach to rapidly review 126 deaths of people who died between March and May 2020, to identify ways to reduce risk to people with a learning disability and/or autistic people. A panel which included experts by experience, acute medics (who treat patients when they arrive in hospital), commissioners, nurses and local authorities recommended actions for acute and primary care providers and commissioners to take to reduce risks to health from the virus. The action plan included guidance on personal protective equipment (PPE), diagnosis/testing, diagnostic overshadowing, hospital passports, shielding and easy read resources, as well as DNACPR and death certification. The plan was shared across the region and through the Association of Directors of Adult Social Services (ADASS).

Resource packs for London care homes

The London learning disability and autism team supported the London enhanced health for care homes team to develop a [London care homes resource pack](#). This gave London care homes clear guidance on keeping residents safe and promoting their health and wellbeing, while ensuring national guidance and good practice were embedded locally. This guidance also aligned with the region's NHS 111 Star lines, which provide rapid access to a GP, and a London COVID-19 [resource pack for primary care](#). Insights from the rapid reviews referred to above informed the resource pack.

COVID vaccination programme

Since November 2020 we have supported the COVID-19 immunisation deployment group and others in planning both awareness raising and the roll out of the COVID vaccine for people with a learning disability and autistic people in an at-risk group and their carers.

Phase 1 of the COVID-19 immunisation programme was designed to protect people at highest risk from serious illness or death. The Joint Committee of Vaccination and Immunisation (JCVI) set out in December 2020 the prioritisation ranking for people at risk, in groups from 1 to 9, largely based on prevention of COVID-19-specific mortality. Older adults in care homes, people aged 80 and over and health and social care workers were given top priority. Adults with Down's syndrome (unless in a high priority group due to age) and people aged 16 to 64 with a severe or profound learning disability were eligible for vaccination in groups 4 and 6 respectively.

This [policy was updated](#) in February 2021 to include everyone aged 16 or older and identified on GP learning disability registers (more than 308,000 in the UK) in group 6. Additional guidance was provided on the appropriate immunisation of children (under 16) with severe neuro-disabilities.

We worked with transforming care partnerships (TCPs), learning disability and autism charities and self-advocacy groups to share information about the vaccination programme as widely as possible in formats that are as accessible as possible including:

- an easy read version of the vaccine invitation letter for PCNs to send to people on GP learning disability registers. This was promoted in the Primary Care bulletin and available on the Primary Care Future Collaboration online platform, to offer appropriate choice of vaccination site – e.g. a GP surgery or local pharmacy rather than a vaccination centre
- a [top tips guide for clinicians](#) vaccinating people with a learning disability
- a [film explaining the COVID-19 vaccine](#) and what to expect after having it, working with Skills for People and Learning Disability England
- an [easy read guide to COVID-19 vaccination](#), working with PHE
- a COVID-19 vaccination easy read consent form for adults, working with PHE
- a resource for the more than 5,000 call handling staff at the NHS 119 COVID vaccination booking service explaining reasonable adjustments, including the need for longer appointments
- training [materials for COVID-19 vaccinators](#) and volunteers, with tips on communicating with people with a learning disability and/or who are autistic as well as any reasonable adjustments they should consider.

These resources have also been cascaded to the COVID-19 clinical and non-clinical workforce, including St John Ambulance, the Royal Voluntary Service and call handlers on the NHS 119 COVID vaccination booking service.

Our regional teams took action to increase uptake of the vaccination offer by people with a learning disability and/or their carers – from ensuring reasonable adjustments are in place to providing people with information in advance.

Vaccination packs in London

London's learning disability nurse leadership network worked with NHS England and NHS Improvement to create a [COVID-19 vaccination pack](#) for supporting people with a learning disability to understand more about the vaccine and what vaccination entails, including how to access appointments. The pack was well received by the London Forum, which brings together people with a learning disability from self-advocacy groups across London. It has been sent to all integrated care system (ICS) vaccination leads in London.

Enfield's adapted testing and vaccination centre

Using the learning from the rapid LeDeR reviews in London, Barnet, Enfield and Haringey Mental Health NHS Trust (BEH - MHT) with support from Enfield's Integrated Learning Disability Service (ILDS) nurses adapted a clinic at Chase Farm Hospital to be suitable for vaccinating people with a learning disability, autistic people and people with serious mental illnesses, and their carers.

The clinic is more spacious than a typical GP surgery and designed to support reasonable adjustments: appointment times are longer and the team can provide some sensory equipment. This vaccination service has been well received and was [featured on BBC News](#).

Enfield Adult Social Care Services, in partnership with Independence and Wellbeing Enfield, also established a dedicated COVID-19 testing centre for vulnerable people who cannot access tests through the government website.

ILDS also developed an [easy read website about COVID](#).

Adapting in lockdown

Working with charities

The three UK-wide lockdowns and area-specific local restrictions have been particularly challenging for people with a learning disability and those supporting them.

From the start of the pandemic we have regularly held webinars with learning disability charities to share key messages and hear their concerns. The insights from this key stakeholder group were heard by the Department of Health and Social Care (DHSC) and helped inform its policy response during the pandemic, e.g. permitting exemptions to restrictions where possible, such as exercising outdoors more than once a day.

We needed to adopt new ways of working to continue to communicate with experts by experience, advocacy groups, charities, families and NHS and social care colleagues. Our raft of essential resources for people with a learning disability, carers and clinicians includes podcasts and YouTube videos, and we have held webinars, Facebook sessions and Q&A sessions.

You're on mute!

We commissioned Ace Anglia, an independent advocacy organisation based in Suffolk, to help six other self-advocacy groups to continue to communicate and work with their members in lockdown. It created an [‘easy read guide to zoom’](#) and films explaining changes to the set-up of doctors’ surgeries and [how a GP will look different in PPE and a mask](#). Along with the peer educator team in Suffolk, Ace Anglia facilitates weekly Zoom sessions at which up to 50 adults with a learning disability and/or who are autistic can talk to a GP and the learning disability liaison nurses about COVID-19 and other concerns. Attendees are encouraged to get an annual health check (AHC) and flu and COVID-19 vaccination, and to take up screening invitations. Membership and confidence in asking health-related questions have grown.

The written and digital information produced for this initiative was promoted through social media and published on [Ace Anglia’s](#) and [Sefton Learning Disability Partnership’s](#) websites. The project was also presented to GPs, organised by the LeDeR lead for Ipswich and East Suffolk.

Ace Anglia hopes to continue delivering the Zoom health sessions until March 2022, with funding from IESCCG and WSCCG – NHS commissioning groups in Ipswich and Suffolk.

“I learn a lot about my health and others.”

Ashley, who has attended the Zoom sessions from Ace Anglia.

A **NHS**
Norfolk and Suffolk
Hill Foundation Trust

Talk Health and Wellbeing

Virtual online meetings every Wednesday at 2:00PM

Questions and answers with the Suffolk Learning Disability Liaison Nurses, other health professionals and Health Peer Educators.

If you are interested in the meetings or have a health-related question you would like to ask:

Email: abbie@aceanglia.com
Or call, text or message 07949 322 812

zoom You will then be sent the Zoom meeting log in details.

To join a session email: abbie@aceanglia.com or phone 07949 322 812

Action from learning in 2020/21: management of medical conditions

Respiratory conditions

Respiratory conditions are a leading cause of avoidable deaths among people with a learning disability and the risk is increased in those with dysphagia (swallowing difficulties). Preventing, diagnosing and managing dysphagia remains a key priority.

Bacterial pneumonia – a lung infection – was the stated cause of death in 24% of adult and 20% of child deaths notified to LeDeR in 2019,² and aspiration pneumonia – following inhalation of anything other than air – in 17% of adults and 3% of children.

Two national pieces of work commissioned last year by the LeDeR team and delayed by COVID-19 are now back on track to be delivered in 2021:

- NHS England and NHS Improvement commissioned guidance on pneumonia and aspiration pneumonia from the British Thoracic Society – whose members include doctors, nurses and respiratory physiotherapists and which champions 'Better lung health for all'. This guidance is being co-produced with people with lived experience.

- The NHS RightCare programme, which makes recommendations to improve healthcare, is developing guides to improve the outcome for patients with respiratory conditions. As part of this it is working with the learning disability and autism programme to develop a RightCare pathway scenario for bacterial pneumonia care.

Dysphagia – learning in action

Dysphagia can cause coughing if food or liquid goes down the 'wrong way' and choking if this blocks a person's airway. It can lead to chest infections and in some cases a form of pneumonia called aspiration pneumonia, a condition requiring urgent medical treatment. Dysphagia has also been linked to avoidable hospital admissions for dehydration and constipation³.

Bedfordshire, Luton and Milton Keynes (BLMK) has led 'learning into action' virtual workshops with partners and stakeholders since November 2020. Using intelligence from LeDeR reviews, breakout sessions and feedback, the BLMK LeDeR steering group has tackled health improvements in areas including AHCs and COVID-19. A recent workshop focused on understanding the current processes for managing dysphagia among people with a learning disability and any barriers to improving service delivery across both health and social care.

² We have quoted the 2019 data here because of the impact of COVID-19 on respiratory deaths data in 2020.

³ Public Health England, 2016: Dysphagia in people with learning difficulties: reasonable adjustments guidance <https://www.gov.uk/government/publications/dysphagia-and-people-with-learning-difficulties/dysphagia-in-people-with-learning-difficulties-reasonable-adjustments-guidance>

By royal appointment

LeDeR reviews in Wakefield have shown that learning disability specialists may not be consulted until a person with a learning disability is very unwell or has been admitted to hospital. A new initiative from the community learning disability team aims to improve respiratory healthcare and how it is managed in the community.

A network of specialist practitioners train primary care nurses to recognise and treat respiratory conditions in the community, using monthly 'lunch and learn sessions' and a webinar on respiratory health and learning disability care. The initiative links to AHCs with the aim of increasing uptake locally and ensuring that everyone with a learning disability has a health check if they want one. The [Queen's Nursing Institute \(QNI\)](#) has selected to support the initiative in 2021, and the [Burdett Trust for Nursing](#), which provides charitable grants to support the nursing contribution to healthcare, has awarded additional funding.

"I am really enjoying being a part of these sessions, it is nice to know we are working towards better care for people with a learning disability from a multidisciplinary team approach. It has also opened my eyes to the health inequalities for people with a learning disability and the difference we can make in our roles as healthcare professionals."

Lauren Dodd, practice nurse in Wakefield. Lauren is new to practice nursing, having previously worked in a local hospital emergency department.

Chest health in Bradford

Bradford prioritised actions to reduce deaths from respiratory issues in response to learning from LeDeR. The learning disabilities health support team at Bradford District Care Foundation Trust (BDCFT) has developed a new respiratory pathway. Their approach was shared with the multidisciplinary team (MDT) and will ensure screening is in place to identify anyone at risk of developing a respiratory condition so that a clear plan to manage their care can be developed. The team has also worked with EasyontheEyeBooks to produce an accessible 'Keeping my chest healthy' care plan with each person, highlighting any support they need with their chest health. More than 40 people with a learning disability supported by the MDT now have a personalised respiratory plan in place.

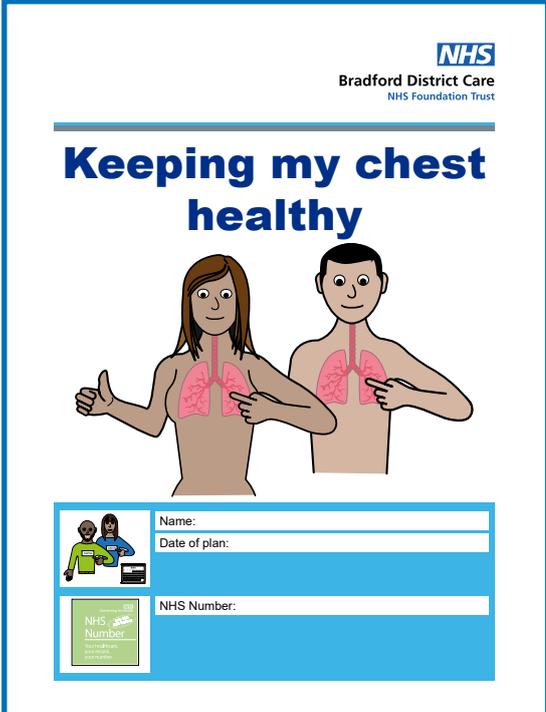
In the wider region, as part of the Keeping my chest healthy work, South West Yorkshire NHS Foundation Trust has recruited an advanced clinical practitioner specifically for respiratory care, and educational resources have been produced with funding from LeDeR for both patients and carers.

Seasonal flu vaccination

Flu vaccination has always been important for people with a learning disability and never more so than this year.

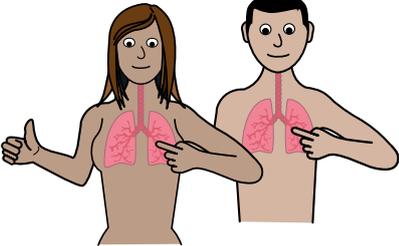
LeDeR reviews highlight that people with a learning disability can miss out on preventative care, including AHCs and flu vaccinations.

Children and adults with a learning disability are identified as a clinically 'at-risk' group, and they and their carers (a family member or support worker) are eligible for a free flu vaccine.



NHS
Bradford District Care
NHS Foundation Trust

Keeping my chest healthy



 Name: _____
Date of plan: _____

 NHS Number: _____

Our winter pressures campaign 2020/21 included a [new toolkit with a learning disability focus](#) to increase flu vaccine uptake, while PHE focused on asking [health and social care workers](#) who support other people to get vaccinated.

Our toolkit shared insights for health and social care workers on language when talking about vaccination, e.g. avoidance of off-putting words like ‘jabs’ or ‘injections’. This may be useful insight for anyone working with the COVID-19 vaccination programme and in any future booster clinics.

We updated an [easy read flu leaflet](#) to support the vaccination campaign, and used a range of methods, including regular webinars, to update primary care colleagues on the importance of inviting people with a learning disability for a flu vaccination.

For GPs we:

- extensively promoted their use of an [easy read letter](#) to invite people with a learning disability for vaccination
- encouraged them over autumn to offer the vaccine to anybody with a learning disability when they attended the surgery for their AHC.



Misfits Theatre Company

The South West region commissioned [Misfits Theatre Company](#) – a theatre and social group led by people with a learning difficulty – to tackle myths around the flu vaccine in their film, [‘Flu vaccination: Just don’t let anything stop you’](#).

The film encouraged people with a learning disability and their carers (family member or support worker) to ‘not delay and get their free flu vaccine today’. It has had more than 5,000 views on YouTube.

Cardiac care

Cardiovascular disease is the general term for conditions affecting the heart or blood vessels. Poor cardiovascular health can cause heart attacks, strokes, heart failure, chronic kidney disease, peripheral arterial disease and vascular dementia.

The most frequently recorded preventable medical causes of deaths in adults with a learning disability were ischaemic heart disease (22%), aspiration pneumonia (12%) and stroke (8%). Ischaemic heart disease, also called coronary heart disease (CHD), is the narrowing of the arteries that supply blood to the heart muscle, depriving this of oxygen⁴.

The [prevention of cardiovascular disease](#) is a major ambition in the [NHS Long Term Plan](#).



⁴ Source: LeDeR report 2020.

Heart health

In the East of England, recommendations from LeDeR learning and local data highlighted that cardiovascular conditions are not always picked up at AHCs or reflected in health action plans, and interventions can be poorly co-ordinated. The region is co-producing resources with the advocacy group ACE Anglia to improve the heart health of people with a learning disability living in Southend, Essex and Thurrock (SET).

New easy read resources on reducing the risk of CHD will cover understanding heart health in the community, raising awareness on healthier lifestyles, improving diagnosis of heart issues and integrating the management of conditions much earlier.

A specialist health provider will audit heart health issues as part of physical health checks and the area will work with primary care to measure the coverage of heart health in AHCs. The findings, resources and integrated pathway will be shared across the region later in 2021.

Identifying deterioration/sepsis

Sepsis is a life-threatening reaction to an infection and a leading cause of death among people with a learning disability. Symptoms may not be obvious and someone may not be able to communicate that they are unwell; their health can deteriorate very quickly.

[Training to help carers](#) and other people recognise the 'soft signs' that someone is deteriorating is essential to saving lives and reducing health inequalities for people with a learning disability across England.

Actions and systems put in place during the first wave of the pandemic provide support in recognising deterioration from any health issue.

A new model of care for supported living

Supported living helps people with various support needs to keep their independence. People in supported living have their own tenancy and are responsible for their bills and cost of living.

Our Midlands team are leading our newly commissioned pilot for the early identification of deterioration in people with a learning disability living in supported environments – this includes people living in their own homes who

have a few hours of outreach support a week, and those living alone or with housemates who have 24-hour staff support – to improve their health outcomes and reduce hospital admissions and A&E attendances.

The regional team is collaborating with the Academic Health Science Networks (AHSNs) for the East and West Midlands and ADASS (the Association of Directors of Adult Social Services) to create this new model of care. The AHSN will test the model of care, developed using the 'PIER' approach to intervention – prevention, identification, escalation or response – to ensure it effectively identifies signs of early deterioration in this group, and with this strong evidence base, interventions developed and tested by people with a learning disability in supported living can be considered for rapid roll out across England.

An 'innovation exchange' in June 2021 will help us learn more from people with a learning disability in supported living, and their carers, about their experiences and what happened when they were unwell. The event will gather innovative approaches already in place and provide insights into use of digital technologies to support people with a learning disability to live happier, healthier lives.

Rapid training for carers

Carers and families are often best placed to spot when someone they care for is unwell. In our approach to improving identification of [‘early warning’ signs](#), we must ensure their concerns are taken seriously and help healthcare professionals quickly respond to concerns.

This year we introduced a ‘train the trainer’ programme, working with third sector partners. By the end of May 2021 more than 7,000 paid and unpaid carers had been trained in Restore2™ mini, and more will be trained through the rest of the year. This tool has been adapted from Restore2™, an award-winning tool to recognise the soft signs of physical deterioration and to improve communication between carers, healthcare staff and GPs, for use with people with a learning disability.

A task and finish group, chaired by a person with a learning disability, worked with learning disability charities⁵ and the West of England and Wessex AHSNs. Health Education England (HEE) and lived experience representatives were also integral to the development of materials and delivering the training.

Some partners are now including this training in their induction training for all new care staff, and the Down’s Syndrome Association plans to offer it to family carers in their network.

“As we are carers what we can’t do is attend distance training, go to exhibitions, travel, etc. It was the first time that training came to us. Now there is a way of understanding what we need to help us fulfil our caring role.”

“This course was so useful – I can’t stop recommending it to friends and family.”

Carers discussing the training they received with a University of Northumbria researcher.

⁵ The full list of organisations is: Three C’s, Choice Support, Dimensions, Health Education England, MacIntyre, NHS @ Home, Northumbria University, Options for supported living, Shared Lives Plus, Silvacare, Skills for Care, Thera, Wessex AHSN, West Hampshire CCG and West of England AHSN.

“Every time I have somebody new on my caseload... I do a Restore 2 now, and I ensure that ...the carers know their soft signs. And I escalate it to the GP. And say, “I’ve done these Restore 2 documents” so that you know if somebody is deteriorating.”

A carer discussing how they’re using the training they received with a University of Northumbria researcher.

Monitoring patients at home

CCGs across England have established [COVID Oximetry @home services](#). Where deemed clinically appropriate, these enable patients at risk of deteriorating with the virus at home, including people with a learning disability and people in care homes, to monitor their oxygen levels and other symptoms to help identify if their health is deteriorating. They record these indicators in a patient diary and have a clear pathway to address any concerns.

In a related initiative, hospitals across the country have set up [COVID virtual wards](#) to support the safe and earlier discharge of COVID-19 patients.

As part of these initiatives more than 300,000 pulse oximeters have been distributed across the country, along with supporting information such as a [pulse oximeter video guide](#) and an [easy read guide on how to use them](#).

Training materials [to support carers](#) are also available on HEE’s e-Learning for Health website.



Project Echo

South Yorkshire and Bassetlaw ICS is delivering remote training in sepsis awareness as well as three further key areas of learning from LeDeR: epilepsy and seizure control, constipation and dysphagia/posture. Care and support staff and clinicians can join short courses lead by St Luke's Hospice (Sheffield) and delivered via [Project ECHO](#), a virtual (Zoom conferencing) learning and support service. The plan is to train or upskill more than 180 residential care providers identified by the Transforming Care Partnership (TCP) and local authorities.

Alongside the Echo training, South Yorkshire TCP is offering educational training in tools including SAMI (Supporting and Maintaining Independence) and Restore2™ mini as well as oximetry to support the early identification of deterioration in physical health and early intervention from GPs and hospitals.

The Humber region's learning disability wellbeing service has also been delivering Echo training to care homes over the last 18 months. It plans to extend this to 200 more care homes and increase topic areas for staff.

From passports to pulse oximeters

Sussex TCP has updated its 'All About Me Passport' to include specific information on the last three hospital attendances – where, why and what happened, to improve information sharing between patients with a learning disability and hospital liaison nurses. In response to LeDeR findings on sepsis, it has also created a guide to sepsis interventions for social care staff, distributed across Sussex, Surrey and local authorities.

The North West is providing Restore2™ training to all care homes, all of which have access to pulse oximeters to recognise deteriorating health. The region is also piloting this remote monitoring approach with people who live in supported accommodation or in their own homes, using Restore2™ mini and pulse oximetry.

The learning disability team in Cheshire are piloting a tool, developed and tested with funding from NHS England and NHS Improvement, for identifying anyone with a learning disability at risk of premature death. Anyone identified at higher risk of COVID-19 was assigned a keyworker from the team. We have also commissioned a researcher to evaluate the outcomes of this approach, particularly in the context of COVID-19.

Significant 7

The LeDeR reviews of two avoidable deaths in Camden led to recommendations to improve clinical support to social care staff working with people in supported living. This inspired work both to provide this clinical support and to prevent hospital

admissions for people with a learning disability. Working together, Camden Council's integrated learning disability service (CLDS) and the learning disability liaison nurse from the Royal Free Hospital identified people with a learning disability, especially those living in supported living, who had had repeat hospital admissions over a five year period. This enabled health and social care partners to identify the common causes of repeat admissions and identify people who may be at risk – so that work can be targeted to prevent these.

University College London Hospital now has a data system that flags admissions of people with a learning disability and the CLDS is planning to review their data too.

We have also worked with CLDS to pilot and implement 'Significant 7+', a health risks management tool for care home staff. Significant 7+ has proved useful for providers of supported living for people with a learning disability: the saving of at least one life has been attributed to it, and its use has reduced 999 calls from supported living as staff are more confident and better able to act on early signs of deterioration.



Diabetes

The NHS Long Term Plan made a commitment to ensure that, in line with clinical guidelines, patients with type 1 diabetes benefit from life-changing flash glucose monitors ('flash' for short). Through a sensor worn on the upper arm glucose levels are monitored and displayed on a mobile app. This information helps the user and their clinical team identify how much insulin needs to be administered to achieve optimal glucose control, reducing the risk of adverse outcomes, ambulance call out and hospital admissions.

The benefits for patients, families and carers include:

- not having to do finger-prick checks
- easier to check glucose levels, so action can be taken earlier
- more confident in managing diabetes.

In autumn 2020, we developed an initiative to give a Flash monitor to all patients with a learning disability and diabetes (whether type 1 or type 2) who use insulin to manage their condition. During 2020/21, we offered the Flash programme to people with a learning disability and raised awareness of this among diabetic consultants, primary care and learning disability teams. An [easy read guide to Flash](#) is also available.



Constipation

Some people with a learning disability are more at risk of constipation than the general population. Constipation is one of the five most common long-term health conditions reported in completed LeDeR reviews (23%) and a third of these reviews mention the prescription of laxatives.

The pandemic has delayed our planned national campaign with our partners to highlight the risks from constipation for someone with a learning disability, but will start this summer.

The 2019 LeDeR report recommended a national clinical audit to determine how chronic constipation might contribute to some deaths. However, a full national audit with input from a wide group of stakeholders could take up to three years to complete and would not provide the timely information we need to take meaningful action now. Instead, we have asked the South West regional team to work with their local health community to deliver a project to:

- discover if constipation or its complications increases hospitalisation or mortality in people with a learning disability and/or who are autistic
- identify national and international best practice guidance and standards for constipation and bowel continence management
- review the academic literature to explore approaches, models of care and services for effectively managing constipation and bowel continence

- outline best practices to improve constipation outcomes for adults and children with a learning disability and/or who are autistic.

We expect this pilot to be completed by winter 2021/22 and the findings will be cascaded via LeDeR to NHS England and NHS Improvement regional teams.



Poo Matters

The NHS Bristol, North Somerset and South Gloucestershire (BNSSG) CCG identified from LeDeR reviews that constipation, a potential cause of sepsis, is a leading long-term health issue in the region.

Discussion of the findings by the regional LeDeR team, a learning disability nurse and the People First group in North Somerset led to the launch in September 2020 of the pilot scheme 'Poo Matters'⁶, in which a [Sirona](#) community learning disability nurse is working with self-advocates from North Somerset People First and directly with people with a learning disability to explore constipation issues.

Informative and engaging online workshops are held on topics including the body and constipation, how to talk about poo and managing health, and online cooking sessions show how to prepare wholesome recipes. The scheme has identified learning points for care homes and support staff, GPs and practice nurses.

The team are looking at next steps to extend the pilot across the area. They are collating teaching resources, developing easy recipes, developing training for practice nurses, GPs, residential staff and carers, and creating a resource pack to support this work.

⁶ This 'Poo Matters' pilot is different from the earlier resources with the same name published in 2019 by NHS England and NHS Improvement, which provided information for families and carers and for health professionals on the warning signs and identification of constipation.

“I didn’t know what constipation was or if I had it. I only pooped once every two or three weeks, I thought that was normal.”

“I was too embarrassed to talk to anyone about poo - I certainly wouldn’t have talked to my GP or anyone else if I had problems. Now I can talk to anyone about poo.”

“The recipes were great, I do much more homemade cooking. I didn’t know constipation affected your health so much. I am less anxious and feel so much better.”

Attendees of the ‘Poo Matters’ online workshops on constipation discuss what they’ve learned.

LeDeR learning on constipation has inspired groups including Mencap in Kingston to run bowel health clinics for their members, with recipes, details on nutrition and dietary fibre.

In Derbyshire the learning disability health facilitation team (HFT) and communications colleagues are working with experts by experience to produce a video that raises awareness of constipation in people with a learning disability. They are promoting bowel health by:

- sharing best practice in regular meetings with community learning disability team (CLDT) managers, nurses, physiotherapists, occupational therapists, continence services and the learning disability health facilitation team
- CLDT physiotherapists training carers in abdominal massage to help with bowel management
- reviewing nurses’ assessments of ‘what and when’ to ensure they are asking all the right questions to screen for the risk of constipation; a tool that determines where extra support is needed for early intervention and treatment is being developed.

What does 30g fibre look like?

Breakfast	Bran flakes (40g) 1 sliced banana		
Snack	Apple		
Lunch	Baked beans wholemeal toast (2 slices)		
Dinner	Baked potato with skin, tuna mayonnaise Salad (lettuce, tomato and cucumber)		
	Low fat yogurt, strawberries and chopped almonds		
			Total: 34.4g

Cancer

The 2020 LeDeR report identified neoplasm (an abnormal or excessive growth of tissue) as the cause of death of 10% males and 12% females with a learning disability; this compares with 31% and 27% in the general population respectively. Neoplasms may be benign (not cancer) or malignant (cancer).

Screening prevents disease and saves lives. Of the 11 NHS England and NHS Improvement run [screening programmes](#) three are for cancers: cervical, breast and bowel. Cervical cancer screening in England is estimated to save 4,500 women's lives a year⁷.

LeDeR reviews tell us that people with a learning disability who have cancer can be diagnosed late; diagnostic overshadowing is sometimes an issue; access to investigations can be poor due to lack of reasonable adjustments and assumptions about ability or willingness to tolerate tests. Improving access to screening for people with a learning disability is a vital learning from local LeDeR reviews.

We continue to work to reduce inequalities in screening, including by informing people of their choices, making services easier to access and supporting people who are diagnosed with cancer, and in partnership with the S7A screening and immunisation team and PHE to increase participation in national screening programmes by under-served groups.

In the last year we have been working to:

- develop the national [health inequalities screening strategy](#)
- improve national screening IT systems – including by recording 'equality' data and improving patient flagging
- explore use of text messaging for appointment reminders and develop translated or easy read materials across all screening programmes
- improve invitation and reminder processes, e.g. by notifying learning disability teams of upcoming screening invitations (where people have given consent)
- develop an advisory group focused on reducing inequalities.

More than 1,100 people 'virtually' attended a national PHE screening inequalities conference in February 2021 to share information, learning and resources to reduce screening inequalities for people with a learning disability. Attendees included people with a learning disability, NHS staff, local authorities, CCGs and cancer alliances. This ground-breaking conference really shone a light on the work of LeDeR and improving health and inequalities.

⁷ NHS Digital/Public Health England <https://www.nhs.uk/Scorecard/Pages/IndicatorFacts.aspx?MetricId=8171>

Two examples of the schemes discussed are given below.

Tackling health inequalities in breast screening

Staff from the Jarvis Breast Screening Centre in Surrey worked with local organisations to improve access to breast screening for women with a learning disability. The council's adult social care team, the NHS foundation trust, the learning disability liaison services and Surrey Choices, which provides adult social care support services, united to tackle health inequalities and improve health outcomes.

The scheme aimed to reduce 'did not attend' breast screening appointments among women with a learning disability, to improve communication and access, to apply reasonable adjustments, to train all staff in accessibility and to improve understanding of the women's needs across the breast screening pathway.

The centre has seen a significant increase in the uptake of breast screening and fewer unused appointments, and the strengthened communication network enables professionals and carers to contact the centre ahead of appointments to discuss reasonable adjustments.

Reducing barriers to breast screening

The 'breast team' at Imperial College Healthcare NHS Trust is delivering a long-term project to reduce barriers to breast screening for women with a learning disability. Their work has included educational events to provide information on screening, including with the use of a breast model. Women with a learning disability have been invited to the screening centre to see the mammography room (where breast x-rays are taken), speak to screening staff and listen to a talk from a woman with a learning disability about her experiences of screening.

Staff who deliver screening have also received training to raise their awareness of working with women with a learning disability and/or autism so they can better apply reasonable adjustments and improve the experience of women with a learning disability generally.

Margaret's legacy

Margaret had a learning disability, lived in supported housing and died from cancer in April 2020.

Before diagnosis, Margaret didn't feel her doctor understood her needs, and she was not flagged on any primary or secondary healthcare system as having a learning disability. She went to hospital appointments for scans and then radiation treatment alone and couldn't understand some of the information she was given.

When it was recognised she needed help, Margaret was supported by the local community learning disability team and St Benedict's Hospice.

Margaret agreed to share her experiences from diagnosis to palliative care in the short film '[Margaret's story](#)' and her legacy has seen improvements in the support services given to people with a learning disability and an increase in awareness across primary, acute and social care.

[A facilitator's pack](#) was developed with support from the North East and Cumbria Learning Disability Network, which links directly with LeDeR, St Benedict's Hospice and the Sunderland Community Learning Disability team. More than 60 people attended 'train the trainer' sessions using these resources, led by [The Macmillan Cancer Learning Disability Project](#).



“Margaret's experience is a very powerful and emotive story and will hopefully improve people's lives - it will enable people to reflect and share good practice.”

An attendee at the Macmillan facilitator training which used Margaret's story to deliver story-based learning around cancer services.

Cervical screening education sessions

Leicestershire used a CCG grant to run two workshops in early 2020 on cervical screening for 24 women with a learning disability who had not accessed screening before. These were facilitated by the learning disability primary care liaison nurses and held in the colposcopy clinic at Leicester's General Hospital. The women were able to see the equipment, learn about the screening procedure, try the tilting chair and practice relaxation techniques.

The team answered questions, discussed consent, and developed health action plans for the women to highlight the individual reasonable adjustments required for their screening. Some women had screening later at their GP practice.

Further Saturday education sessions – and screening – are planned, with funding and support from the colposcopy team.



Epilepsy

Epilepsy is a condition that affects the electrical activity in the brain causing seizures. It is one of the most common causes of death among people with a learning disability.

While around one in 100 of the general population has epilepsy⁸, nearly one in three people with a mild to moderate learning disability has epileptic seizures – and the more severe their learning disability, the more likely they are to have the condition.

Warning signs are seen in 90% of people who have a diagnosis of epilepsy and die suddenly. These should inform care plans, support risk reduction and reduce mortality.

Raising awareness on epilepsy risks

A recent study⁹ found that more than 33% of people with a learning disability did not have an epilepsy care plan and 100% were unaware of the risk of sudden death due to epilepsy.

NHS England and NHS Improvement has awarded a grant to SUDEP Action to develop epilepsy resources and videos which will be co-produced by people with a learning disability and their carers.

A new collaboration from SUDEP Action and Ardens (a healthcare informatics organisation) will also see the [SUDEP and Seizure Safety Checklist](#) – an epilepsy safety tool – downloadable to more than half the GP surgeries in England who currently use EMIS Health or SystmOne patient record systems. The resource can be used to discuss and manage epilepsy risks to improve safety. It also signposts people to use the EpSMon mobile phone app for epilepsy risk self-monitoring between GP appointments.

Working with the EpSMon research lead at Cornwall Partnership NHS Foundation Trust, SUDEP Action will also use our grant to discover how the [EpSMon mobile phone app](#), which is free for users, could be made accessible to people with a learning disability, and potentially tied into AHCs with GPs.

⁸ Sources: Epilepsy Society and SUDEP Action.

⁹ British Epilepsy Association (2020) Seizure and sudden unexpected death in epilepsy (SUDEP) characteristics in an urban UK intellectual disability service. <https://pubmed.ncbi.nlm.nih.gov/32485614/>

“As risk has risen through the pandemic, this collaboration will help speed up person-centred appreciation of SUDEP and epilepsy risk, with a view to supporting advocacy and care planning to help keep people safe.”

Jane Hanna OBE, Chief Executive SUDEP Action



Wednesdays at one in the valley

Thames Valley (Berkshire, Buckinghamshire, Milton Keynes and Oxfordshire) is using lunch breaks to address health inequalities for people with a learning disability. NHS staff, providers and the learning disability voluntary sector staff combined their expertise to deliver ‘Wednesday At One’ from November 2020, a series of eight talks and insights from people with lived experience and specialists, and for carers, families and clinicians to improve their knowledge of issues affecting the health and life-expectancy of people with a learning disability. The subjects discussed included recognising vulnerability and risks in people with epilepsy, promoting healthy lifestyles, dysphagia, respiratory illnesses and end of life care planning. The talks are available on the Oxford Health NHS website.

Action from learning in 2020/21: changing how we work

DNACPR – do not attempt cardiopulmonary resuscitation

A DNACPR is the decision not to attempt cardiopulmonary resuscitation should a person experience cardiac or respiratory arrest. Decisions relating to DNACPR must always be made on an individual, person-by-person basis and never based on the presence of a learning disability or autism alone.

While LeDeR reviewers report the significant majority of DNACPR decisions are completed correctly (LeDeR annual reports: 76% in 2018, 73% in 2019, 71% in 2020), they consider a small proportion are inaccurately or inappropriately completed. Of these 13 in 2018, 12 in 2019 and 14 in 2020 included evidence that the rationale for the decision was inappropriate, e.g. the use of the term 'learning disabilities' [sic].

NHS England and NHS Improvement published guidance before and during the COVID-19 pandemic emphasising that learning disability and/or autism should never be used as a rationale for a DNACPR decision and that such decisions must only be made on an individual basis in consultation with the individual or their family. This messaging has been firmly maintained throughout the pandemic. Our guidance on DNACPR is listed in our [COVID-19 action from learning report](#), published in November 2020.

In addition, the [2020/21 General Medical Services \(GMS\) contract Quality and Outcomes Framework \(QOF\)](#) (published in September 2020) states that all DNACPR decisions for people with a learning disability must be reviewed to ensure they have been appropriately determined and continue to be clinically indicated.

Protect, respect, connect

The CQC's review Protect, respect, connect – decisions about living and dying well during COVID-19 (March 2021) found variation in people's experiences of DNACPR decisions during the pandemic. While there were some examples of good practice, the CQC also heard from people who were not properly involved in decisions or were unaware that such an important decision about their care had been made.

Among its recommendations CQC calls for:

- the establishment of a ministerial oversight group, working with partners in health and social care, local government and the voluntary sector, to take responsibility for delivering improvements in this vital and sensitive area
- improved information, training and support
- a consistent national approach to advance care planning
- improved oversight and assurance.

More specifically, the report names DHSC and NHS England and NHS Improvement as the lead organisations responsible for actioning the following recommendation:

People, their families and representatives need to be supported, as partners in personalised care, to understand what good practice looks like for DNACPR decisions. This should include what their rights are and how to challenge and navigate experiences well. In addition, there needs to be positive promotion of advance care planning and DNACPR decisions, as well as a more general focus on living and dying well. To do this, there needs to be more widely publicised and accessible information available via a national campaign and in partnership with the voluntary sector and advocacy services.

NHS England and NHS Improvement will work closely with DHSC over the coming months to action this recommendation as part of the system-wide response to the CQC's findings.

End of life care

The Royal College of Physicians published guidance on [palliative and end of life care during COVID-19](#), and the Royal College of General Practitioners its [COVID End of Life Community Charter](#) giving the ethical principles GPs should follow.

Working with older people

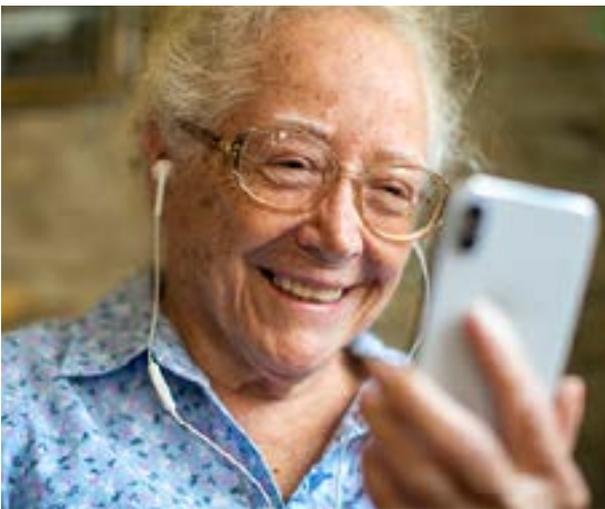
Life story work with people with dementia, supported by their families and/or carers, helps build a personal biography of memories, photos, music and important events.

In response to a local LeDeR recommendation on the importance of knowing a person's 'life story' to promote personalised care at the end of life, West Sussex learning disability task group successfully bid for funding from the West Sussex dementia strategy and the CCG to deliver 'life story' training in the region.

Facilitated by a life story writer and a learning disability dementia expert, the learning from life story sessions will be adapted for anyone with or at risk of early-onset dementia and older people living in shared lives (where a person with a learning disability lives with carers, often as part of a family). Attendees will commit to delivering life story work before the project is evaluated for sustainability.

A series of training workshops was also offered to anyone caring for or supporting someone with a learning disability, including shared lives carers, care managers, community learning disability teams and staff in day services.

The life story initiative is part of a wider task and finish group which will also look at increasing awareness of those with a learning disability in all communities and improving the use of technology to maintain independence. A useful guide to life story work with people with a learning disability is available from the MacIntyre Charity.



Coordinated care

A scheme in London is addressing guidance to put people with a learning disability and their families at the heart of decision-making. All community nurses in South West London, including acute learning disability liaison nurses, have been trained in Coordinate My Care (CMC). This service enables urgent care patients or their carers to start an online advance care planning questionnaire – ‘myCMC’ – which then goes to a doctor or nurse who knows them to add the diagnosis, medical details, resuscitation status, medications and any wishes for the urgent care services to follow in an emergency. Urgent care services such as NHS 111, out-of-hours GPs, ambulance crews and emergency departments can access these completed plans.

Reasonable adjustments

People with a learning disability can have a poorer experience and outcomes when accessing healthcare. [The Equality Act 2010](#) and the [Public Sector Equality Duty](#) require that all NHS trusts and social care providers must make reasonable adjustments to 'remove any barriers – physical or otherwise – that could make it difficult for disabled people to use their services or prevent them from using them altogether'.

Reasonable adjustments will vary from person to person.

Raising the digital flag

We have worked with NHS Digital to create a 'reasonable adjustments flag' for patient records. This will enable health and care staff to record, share and view details of a person's reasonable adjustments across the NHS, so that they are known about wherever the person is treated. This work was delayed by the pandemic but has now resumed.

A pilot in two NHS trusts – Devon and Gloucestershire – checked the technical capability of the system built on NHS Spine, and we will work with 30 'early adopter' organisations to refine the system this summer, before making it available to local systems.

We have also produced a short film about [what digital flagging means](#) for patients and how sharing information can help staff in health services learn about the right way to work with people with a learning disability and/or who are autistic.

Throughout the pandemic, we have produced or co-produced easy read guides for people with a learning disability and new training materials or resources to support clinicians and others. This collateral supports improved communication and application of reasonable adjustments at every possible stage. Resources include:

- a [podcast on vaccinating people](#) with a learning disability and autistic people
- a [short film about vaccines](#) – what they are and why they are important
- a reasonable adjustments film in collaboration with [Misfits Theatre Company](#).

We have also supported our partners to create resources explaining all aspects of the pandemic – from social distancing and shielding, to what to expect after vaccination.

Annual health checks (AHCs)

The learning disability and autism programme is committed to ensuring that 75% of people with a learning disability on GP learning disability registers receive an AHC to identify health issues before they become a problem. This priority for the NHS has not wavered during the pandemic.

Last year all NHS commissioners and providers were reminded that GP practices should continue to ensure that everyone with a learning disability is identified on their learning disability registers and that AHCs are completed for them. They were advised that these should be in person where safe to do – that is the patient was not shielding or in a local lockdown – and that reasonable adjustments should continue to be made to meet individual needs. Mental health trusts were also made aware of their responsibility to support delivery of AHCs to their eligible inpatients.

Working with organisations including Ace Anglia, Mencap, Dimensions, Learning Disability England, Contact and the National Network of Parent Carer Forums, we formed expert groups to develop bespoke campaigns in October 2020 targeting people with a learning disability, general practice (all staff) and families/carers. The message was that people with a learning disability and/or their carers should make sure that they are on their GP's learning disability register and receive an AHC. We had planned to deliver training in person on AHCs but instead provided online sessions.

Putting people first in Merseyside

Uptake of AHCs in Liverpool and Sefton has steadily increased following the launch in September of an NHS Mersey Care learning disabilities community team-led project to support people to attend these checks.

People First Merseyside, a self-advocacy charity for adults, created an education programme for people with a learning disability to encourage their members and others to have their health checks. They developed an annual health check booklet explaining the need for a yearly check-up, and to empower people to request an appointment. The booklet has been promoted to GPs, CCGs and other healthcare professionals and can be used by anyone encouraging AHCs.

As COVID-19 restrictions are relaxed the group plans to share their experiences at roadshows in community venues, and directly with learning disability groups, to provide peer-to-peer education on uptake of these vital health checks and their quality across Cheshire and Merseyside.

Liverpool has been hosting events on Saturdays that people with a learning disability in one PCN can attend for their AHC, carried out by a physician associate (a healthcare professional who can diagnose illnesses and prescribe medications). Health action plans are also developed on the day and reasonable adjustments provided where necessary.

Mystery patients

Sunderland CCG has developed creative ways to ensure that AHCs happen and are of good quality, such as getting GPs' agreement to be rated by a 'mystery patient'. Feedback from this initiative has helped improve people's experiences of attending appointments, increase attendances, test how accessible they are and support GPs to understand how they can improve care and treatment.

The community learning disability team in Sunderland has produced and distributed a resource pack to every GP practice in their network and created a new 'AHC risk stratification tool' that supports GPs to establish a person's health risks, and identify whether they need more monitoring, further tests or a follow-up appointment. This has been extremely helpful in prioritising patients at greatest risk during the pandemic.

Health checks in the West Midlands

The community learning disability nursing team or 'PAMHS' in the Black Country, which works to 'promote access to mainstream health services', are developing a network of local learning disability champions in primary care to encourage the uptake of AHCs. They are also working to ensure consistency in the messages and communications sent to people on their learning disability register. PAMHS are completing the PHE quality check tool to audit the quality of AHCs and help practices identify where they can make improvements.

LEARNING DISABILITY ANNUAL HEALTH CHECKS



A GUIDE TO ANNUAL HEALTH CHECKS FOR ADULTS WITH LEARNING DISABILITIES

People First

STOMP-STAMP (Medication)

Psychotropic medicines affect how the brain works and include medicines for psychosis, depression, anxiety, sleep problems and epilepsy. Sometimes they are given to people because their behaviour is seen as challenging.

People with a learning disability, autism or both are more likely to be given these medicines than other people.

[STOMP](#) (Stopping Over Medication of People with a learning disability, autism, or both) and [STAMP](#) (Supporting Treatment and Appropriate Medication in Paediatrics) are the national programmes led by NHS England and NHS Improvement to stop the over use of these medicines, by ensuring they are used cautiously, monitored regularly and challenged as soon as they are no longer needed.

We are increasing efforts to engage stakeholders with the current guidance around medicines, to reinforce that:

- the decision to prescribe should be based on a holistic review of a person's wellbeing – their physical and mental health as well as their overall quality of life
- medication should be used in line with NICE guidance and supported by non-medication alternatives to managing behaviour
- learning from LeDeR reviews should help identify trends in medication use and the risk of inappropriate prescribing.

Over the next year the STOMP-STAMP programme aims to:

- re-engage and educate people with a learning disability, family members and health and social care professionals about STOMP-STAMP
- engage with new partners by producing additional STOMP resources for autistic people, and translating resources into eight [different languages](#) within multicultural communities
- produce a STOMP educational platform with MindEd to raise awareness about STOMP
- deliver a pilot project in primary care to understand how psychotropic medications are prescribed to children and young people
- provide national data to understand prescribing trends in primary care
- support the [Specialist Pharmacy Service \(SPS\)](#) to upskill primary care pharmacists to deliver high quality STOMP health checks.

Overmedication work in the North East

The North East is addressing issues around overmedication with staff training and recruitment to specific posts, and auditing and mapping of children's care and treatment. New sleep support and sleep clinics are addressing some of the issues children, young people and families experience.

NHS England and NHS Improvement's regional team led two 'refresher' webinars in 2021 for GPs, pharmacists, social prescribers, health and wellbeing coaches and others on positive support and STOMP-STAMP. More than 350 health professionals attended.

Future plans include mapping of services and support available to adults and ensuring local LeDeR learning informs action plans.



Inequalities for people from minority ethnic communities

Every LeDeR steering group has been asked to identify a named lead for their area who will ensure that the challenges faced by people from minority ethnic communities are considered and addressed as part of local LeDeR work. Their role includes ensuring that reviewers understand the challenges faced by people in accessing services, establishing links with organisations that represent minority ethnic groups, raising the profile of LeDeR and increasing the notification of deaths from minority ethnic communities proportionate to the local communities.

Our new [LeDeR policy](#) outlines the requirement to carry out a focused review for every person from a minority ethnic community to learn how to address any additional inequalities relating to race and ethnicity.

We have commissioned the [Race Equality Foundation](#) and [Learning Disability England](#) to undertake work to understand the inequalities faced by people with a learning disability from minority ethnic communities and to identify targeted actions to address these. Focus groups with people with a learning disability and family carers have started, to gather insights into lived experiences and ensure a solid foundation for this work in 2021.

We have also commissioned Learning Disability England to work with self-advocacy groups to support the development and strengthening of self-advocacy support or self-advocacy organisations to provide culturally competent and inclusive support and to encourage uptake of COVID-19 vaccination among people from minority ethnic communities with a learning disability.

We [issued guidance](#) in August 2020 directing local systems to speed up their work to tackle health inequalities for people with a learning disability, and in this stressed the need to increase flu vaccine uptake among people with a learning disability, especially those from minority ethnic communities.

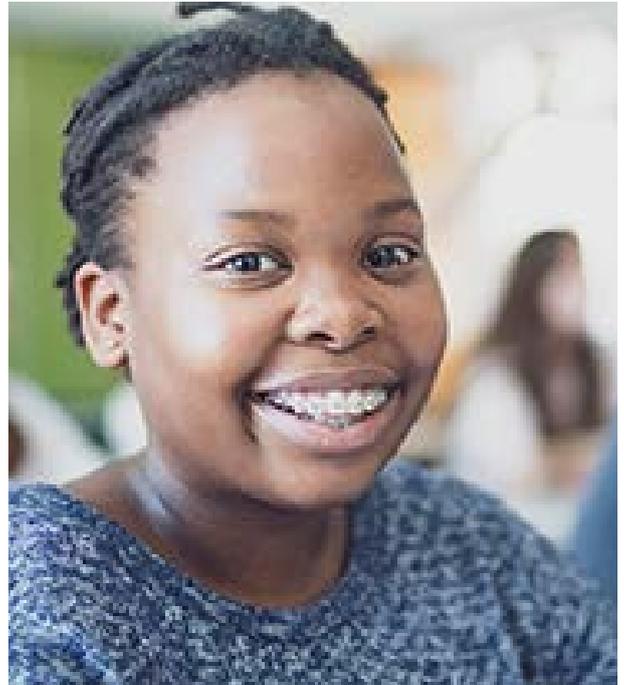
Our operational plan to address inequalities includes goals for systems to improve access, experience and outcomes for all groups.

We worked with a psychiatrist in Birmingham – who is researching poorer service engagement by minority ethnic groups – to produce a leaflet on the prescription of medicines such as antidepressants and anti-epileptics, and translated this into eight languages: Urdu, Punjabi, Somali, Polish, Romanian, Bengali, Gujarati and Hindi. These are available for download from the [NHS STOMP website](#).

A new outreach worker role in Norfolk

Norfolk and Waveney CCG has created a new full-time role for a learning disability outreach worker with a background in health promotion. They will identify, engage and support people with a learning disability and/or who are autistic to improve their health and to access health services – including those from minority ethnic communities, transient communities, refugees and asylum seekers.

The outreach worker will help those not registered with a GP to register so that their care continues, and inform them of the importance of having an AHC and seasonal flu vaccinations. Particular emphasis will be placed on identifying high risk individuals who have never had an AHC or not for several years.



Terms used

AHC – annual health check. Anyone aged 14 or over who is on their GP's learning disability register can have a free annual health check once a year. These checks can identify health issues before they become a problem.

AHSN – Academic Health Science Networks. There are 15, set up by the NHS in 2013 to help the service develop innovations to improve healthcare.

CCGs – clinical commissioning groups. These are clinically-led statutory NHS bodies responsible for planning and commissioning healthcare services locally.

DHSC – The Department of Health and Social Care. The ministerial department that supports ministers in leading the nation's health and social care to help people live more independent, healthier lives for longer.

DNACPR – do not attempt cardiopulmonary resuscitation. A DNACPR or DNAR is an advance decision not to attempt cardiopulmonary resuscitation should a person experience cardiac or respiratory arrest.

HEE – Health Education England. This NHS organisation supports the delivery of healthcare and health improvement to patients and the public across England by ensuring that the workforce of today and tomorrow has the right numbers, skills, values and behaviours, at the right time and in the right place.

ICS – integrated care system. A group of health and care organisations who come together to improve the health of people in their area.

Learning disability – A learning disability affects the way a person learns new things throughout their lifetime. A learning disability affects the way a person understands information and how they communicate. This means they can have difficulty understanding new or complex information, learning new skills and coping independently.

Learning Disability and Autism Advisory Group – a group of 15 experts by experience (people with a learning disability, autistic people and family carers) who help NHS England and NHS Improvement with work that affects people with a learning disability.

LeDeR – Learning from lives and deaths – People with a learning disability and autistic people is a service improvement programme which aims to improve care, reduce health inequalities and prevent premature mortality of people with a learning disability and (from 2021) autistic people by reviewing information about the health and social care support people received. It is funded by NHS England and NHS Improvement.

NHS England and NHS Improvement – since April 2019 NHS England and NHS Improvement have worked as a single organisation to support the NHS and deliver improved care.

NHS Spine – this supports the information technology (IT) systems for health and social care in England, linking over 23,000 systems in 20,500 organisations.

PAMHS – Promoting Access to Mainstream Health Services. PAMHS nurses provide a single point of contact for a seamless journey through healthcare systems for an individual with a learning disability and their carer(s).

Pulse oximeter – usually placed on a fingertip, these meters are a non-invasive way of measuring someone’s level of oxygen in their blood.

Restore2™ and Restore2™ mini
– Recognise Early Soft Signs, Take Observations, Respond, Escalate; tools used to identify deterioration in health.

Task and finish group – a group of people who are responsible for delivering a specific objective within an agreed timeframe; they report back to a wider group with any recommendations, action plan or evaluation.

TCP – Transforming Care Partnerships. These are made up of CCGs, NHS England and NHS Improvement’s specialised commissioners and local authorities. They work with people with a learning disability and/or who are autistic and their families and carers to agree and deliver local plans.

Appendix 1: Update on actions by NHS England and NHS Improvement

This table shows our progress towards fulfilling LeDeR commitments made last year. It covers the period summer 2020 to spring 2021.

Theme	University of Bristol recommendation	Agreed action	Update for 2020/21
Racial inequalities	A continued focus on the deaths of all adults and children from minority ethnic groups is required.	LeDeR steering groups to be asked to identify a lead for minority ethnic group inclusion.	<p>Every LeDeR steering group has been asked to identify a named lead who will ensure that the challenges faced by people from minority ethnic communities in their local area are considered and addressed as part of LeDeR. We have advised CCGs of the requirements of this role.</p> <p>The new LeDeR policy states that every death of a person from a minority ethnic group should have a focused LeDeR review, that ICSs should ensure that reviewers are representative of their local population and that they understand the local communities they work in, including their cultures and beliefs, including around learning disability and autism, bereavement and death.</p> <p>Every area is also expected to continue to share any local good practices that could be cascaded and used in other areas or across LeDeR.</p>
		We will explore including the needs of people with a learning disability from minority ethnic communities in the revised NHS Equality Delivery System.	The COVID-19 pandemic meant any work related to the revision of the NHS Equality Delivery System was paused. As part of NHS England and NHS Improvement's Health Inequalities Improvement Programme work with the Learning Disabilities and Autism team, we remain committed to addressing the needs of people with a learning disability, recognising the role of intersectionality such as ethnicity, and the considerations and adjustments that need to be made in addressing these.

Theme	University of Bristol recommendation	Agreed action	Update for 2020/21
<p>Acute deterioration</p>	<p>Adapt (and then adopt) the National Early Warning Score 2 (NEWS2) regionally, e.g. as Wessex has done with Restore2™, ensuring it captures baseline and soft signs of acute deterioration in physical health for people with a learning disability by:</p> <ul style="list-style-type: none"> • involving people with a learning disability and their families, and professional organisations • disseminating for use across acute, primary and community settings. 	<p>We will evaluate the use of NEWS2 and Restore2™ and other early warning approaches to ensure that they meet the needs of people with a learning disability and adapt documentation to reflect any required changes.</p>	<p>Northumbria University is evaluating the effectiveness of Early Warning Scoring (EWS) tools in identifying signs of deterioration in people with a learning disability. This includes a scoping exercise to identify the type and distribution of different EWS tools in use across England, together with a qualitative study to explore the lived experience and gather evidence on carers' experiences of:</p> <ul style="list-style-type: none"> • recognising the early signs of illness and deterioration in the health of adults with a learning disability or autism • using educational tools or training that help them to assess the health of adults with a learning disability or autism and their views on their usefulness • getting timely help and treatment. <p>Interviews have been conducted with paid and unpaid carers who provide care in the following settings:</p> <ul style="list-style-type: none"> • supported living environments • family homes • social care home providers. <p>The data has been collected and analysis is underway. The project and final report will be available in October 2021.</p>

Theme	University of Bristol recommendation	Agreed action	Update for 2020/21
			<p>With support from the Academic Health Science Network (AHSN) and health and care partners, pulse oximetry, Restore 2 and Restore2™ mini have been piloted in Devon (among people living with families and in supported living) and in Dorset (among people with CHC funding and people in care homes).</p>
		<p>We will implement at least one pilot programme using Restore2™, virtual wards and oximeters to support care staff to identify early signs of deterioration.</p>	<p>Remote monitoring will be rolled out to other ICSs in the South West, to improve health outcomes and build the confidence of staff and family carers in providing support.</p> <p>Other pilots are underway, e.g. in South Yorkshire and the North West.</p> <p>CCGs across England have established COVID Oximetry @home services to monitor patients at risk of deteriorating with the virus at home where deemed clinically appropriate, including people with a learning disability and living in a care home.</p> <p>Pulse oximetry and virtual wards, including for people with a learning disability, have been rolled out across England at speed due to the pandemic.</p>
		<p>We will train 5,000 paid and unpaid carers in the use of Restore2™ mini to help them detect early signs of deterioration.</p>	<p>We have established a training programme using a train the trainer model. By the end of May 2021, more than 7,000 paid and unpaid carers had been trained in Restore2™ mini.</p>

Theme	University of Bristol recommendation	Agreed action	Update for 2020/21
Respiratory	Consider the need for timely, NICE evidence-based guidance that covers prevention, diagnosis and management of aspiration pneumonia. The outcome of such considerations should be shared with DHSC and NHS England and NHS Improvement.	We have commissioned a toolkit and guidance from the British Thoracic Society around pneumonia and aspiration pneumonia.	The need for experts, particularly respiratory medicine experts, to work on the frontline in response to the COVID-19 pandemic delayed this work. It has now started, including by convening a co-production group, and is due to be completed by spring 2022.
	NHS RightCare to provide a toolkit to support systems to improve outcomes for adults and children at risk of aspiration pneumonia.	NHS RightCare to provide a set of resources to support systems to improve patient outcomes for adults and children at risk of aspiration pneumonia.	This work was delayed by the COVID-19 pandemic. It has now started. Experts by experience are working with the programme and it is due to be completed by spring 2022.
Constipation	A national clinical audit of adults and children admitted to hospital for a condition related to chronic constipation. One way this could happen is through the National Clinical Audit and Patient Outcomes Programme.	We will work across the system to find the most appropriate route to understanding the prevalence, causes and consequences of chronic constipation.	We have commissioned a pilot project that will review hospitalisation and mortality data, identify national and international best practice guidance and standards, and review the academic literature to determine best practice approaches to improving constipation outcomes for adults and children with a learning disability.

Appendix 2: COVID-19 response - progress on commitments

The University of Bristol Learning Disability Mortality Review (LeDeR) programme [published an interim report](#) on the deaths of people identified as having a learning disability from COVID-19 in England in spring 2020. In response, we published [Action from learning: deaths of people with a learning disability from COVID-19](#) in November 2020.

The table below summarises our progress in fulfilling the commitments that we made in our response report.

Theme	Agreed action	Update for 2020/21
Identifying deterioration in health	<p>CCGs are being asked to roll out COVID-19 virtual wards to monitor patients at risk of deteriorating with COVID-19 at home, including in care homes, for people with a learning disability</p> <p>We will progress work to train at least 5,000 paid and unpaid carers of people with a learning disability in the use of Restore2™ mini tool, which uses 'soft signs' to help carers identify deterioration in the health of people they care for.</p> <p>We will work with the Royal College of Physicians (RCP) to produce a toolkit on the management of deterioration in the health of people with a learning disability in acute hospital settings.</p> <p>NHS South West regional team to roll out the use of pulse oximetry and Restore2™ across community settings in the region in early 2021.</p>	<p>CCGs created virtual wards to monitor patients with a learning disability and others at risk of deteriorating with COVID-19 at home or in care homes.</p> <p>By the end of May 2021 more than 7,000 carers had been trained in Restore2™ mini. This will help carers detect the early signs of deterioration in a person they are supporting and communicate these to healthcare staff, including GPs.</p> <p>This work was delayed as many experts needed to work in frontline services to support the response to the COVID-19 pandemic. Work with RCP will progress through 2021.</p> <p>With support from the Academic Health Science Network (AHSN) and health and care partners, pulse oximetry, Restore2 and Restore2™ mini have been piloted in Devon (among people living with families and in supported living) and in Dorset (among people with Continuing Health Care funding and people in care homes).</p> <p>Remote monitoring will be rolled out to other ICSs in the South West, to improve health outcomes and to help grow the confidence of staff and family carers in providing support.</p>

Theme	Agreed action	Update for 2020/21
	<p>North East and Yorkshire, overseen by the regional team, to roll out sleep activity monitoring and Restore2™ training to 1,260 care workers who support 3,062 individuals. They will provide pulse oximeters to staff working in 180 care settings across Sheffield, Doncaster and Rotherham, including some smaller care homes and supported living units.</p>	<p>South Yorkshire TCP is offering educational training in the SAMI (Supporting and Maintaining Independence), Restore2™ mini tool and oximetry to support the identification of early deterioration in physical health and early intervention from GPs and hospitals. This training has certified continued professional development accreditation.</p>
<p>DNACPR</p>	<p>GP practices, via the Quality and Outcomes Framework, to review all DNACPRs for people with a learning disability registered with their practice and confirm that they were determined appropriately and remain clinically appropriate.</p>	<p>This was included in the GP contract for 2020-21.</p>
<p>Death certification</p>	<p>The learning disability and autism programme is working closely with the National Medical Examiner to inform the work of medical examiners in relation to the deaths of people with a learning disability. Medical examiners will, where necessary, support bereaved families and work with all doctors who write death certificates to use the correct terminology in all parts of the medical certificate of cause of death (MCCD).</p>	<p>Medical examiners will provide independent scrutiny of the causes of death of a person who dies in hospital but is not referred to a coroner and, over time, every death in the community not referred to a coroner.</p> <p>The National Medical Examiner convened a round table discussion, attended by the National Clinical Director for Learning Disability and Autism, and will issue a good practice paper for medical examiners in the coming months. This will reinforce the importance of working sensitively with the bereaved following the death of a person with a learning disability and/or autism.</p> <p>The paper will reiterate the official guidance for doctors completing MCCD, updated by the Office for National Statistics and the General Register Office, in April 2020 to reflect Coronavirus Act provisions which state 'learning difficulties [sic] should not be the only cause of death' and particularly not in Part 1, as 'the more immediate mechanism(s) or train of events leading to death must be made clear'.</p>

Theme	Agreed action	Update for 2020/21
<p>Diagnostic overshadowing</p>	<p>The learning disability and autism programme will work with the national NHS 111 team to improve access to the service.</p> <p>GP practices across England to be asked to use their clinical judgement to determine who on their GP register should be considered at higher risk of serious illness from COVID-19 and to take appropriate action to advise those individuals and their carers (as appropriate) of the need to take additional precautions.</p> <p>GPs to be reminded about the risks of diagnostic overshadowing in people with a learning disability and that the presentation of people with a learning disability with COVID-19, or another condition where deterioration can be rapid, may be different to that for the general population, so that people with a learning disability have appropriate and timely access to healthcare.</p>	<p>We worked with NHS 111 to maximise the accessibility of its telephone service for people who are autistic or have a learning disability and to review the accessibility of NHS 111 online.</p> <p>We also worked with NHS 111 to develop the easy read 111 first leaflet and shared this with stakeholder networks, to make sure that people with a learning disability and autistic people are aware of this new service and reminded of their right to ask NHS 111 for reasonable adjustments.</p> <p>This was communicated to GPs in a letter from Simon Stevens and Amanda Pritchard and reiterated in primary care webinars.</p> <p>This was communicated to GPs via updates to primary care and reiterated in primary care webinars.</p>
<p>Reasonable adjustments</p>	<p>Remind leaders of relevant clinical organisations of the need to make reasonable adjustments, including highlighting the role of staff with particular experience and expertise in learning disability and health liaison, e.g. learning disability nurses, in ensuring that reasonable adjustment needs are understood by frontline clinicians and are implemented.</p>	<p>This was communicated to clinical organisation chief executives and resources were developed to support healthcare staff including:</p> <ul style="list-style-type: none"> • NICE clinical specialty guidance on the care of people with a learning disability and autistic people during COVID-19 • a COVID-19 Grab and Go guide and guidance notes.

Appendix 3: Recommendations from the 2020 University of Bristol LeDeR report and our proposed actions in response to them

No.	University of Bristol recommendation	Audience	Proposed action by NHS England and NHS Improvement
1.	LeDeR reviews to be undertaken through the lens of greater racial awareness.	NHS England and NHS Improvement	<p>NHS England and NHS Improvement recognise the significant health inequalities faced by people with a learning disability and who are from minority ethnic groups.</p> <p>The new LeDeR policy sets out a requirement for focused reviews to be completed for every death of a person from a minority ethnic community.</p> <p>All ICSs are required to appoint a named individual who will ensure that the healthcare inequalities faced by people with a learning disability from minority ethnic communities within that ICS are considered and addressed where this is possible as part of LeDeR, including increasing notifications of deaths from minority ethnic communities proportionate to the local communities within the ICS.</p> <p>The training for LeDeR reviewers and local area contacts will emphasise the importance of considering factors related to ethnicity and inequalities when undertaking reviews.</p> <p>We will pilot a new approach to annual health checks, working with acute and mental health trusts and in partnership with primary care, including a focus on how we can engage with people from minority ethnic communities to increase their uptake of AHCs.</p>

No.	University of Bristol recommendation	Audience	Proposed action by NHS England and NHS Improvement
2.	<p>Local authorities to ensure that Joint Strategic Needs Assessments (JSNA) collect and publish local data on the health needs of children and adults with learning disabilities¹⁰, capturing any characteristics that relate to specific ethnic groups. Integrated Care Systems (ICS) and their commissioned Primary Care Networks to take actions to reduce any disparities between people from different ethnic groups when planning local services for people with learning disabilities and their families. Accountability for this to be monitored at regional level, and by NHS England and NHS Improvement.</p>	<p>Local authorities, NHS England and NHS Improvement, ICSs, NHS Race and Health Observatory</p>	<p>Reducing health inequalities is a priority for NHS England and NHS Improvement.</p> <p>The new LeDeR policy requires ICSs to submit quarterly reports on Action from Learning to NHS England and NHS Improvement regional teams for monitoring and assurance. This includes a requirement to report on actions to reduce health inequalities among people from different minority ethnic communities.</p> <p>We are concerned about the health inequalities that the University of Bristol continues to identify in its LeDeR annual reports, and will be commissioning the Race and Health Observatory to work with us to understand what further action we can take to tackle these health inequalities.</p>
3.	<p>A nationally endorsed standard resource is required, with local flexibility, that provides information for people with learning disabilities and their families about legal rights and entitlements, national services and how to access them, and local sources of support. Mechanisms must be in place for its effective distribution, particularly to people from minority ethnic groups.</p>	<p>NHS England and NHS Improvement</p>	<p>We will work with our partner agencies, including the Department of Health and Social Care, to identify how best to ensure that people with a learning disability and their families are signposted to information about healthcare related rights, entitlements, national services and local sources of support.</p>

¹⁰People with learning disabilities’ is the University’s preferred phrasing, but we refer to ‘people with a learning disability’.

No.	University of Bristol recommendation	Audience	Proposed action by NHS England and NHS Improvement
4.	Strategically planned, long-term, targeted, joint investment is needed to strengthen partnerships with local communities and provide support for peer-to-peer networks, to build on and future-proof existing contacts and structures within local communities and increase trusted word-of-mouth communication and information sharing.	Local authorities, ICSs, Primary Care Networks	<p>By prioritising the needs of those who experience the poorest health outcomes, the NHS is better able to improve access to services, reduce health inequalities in our communities and make better use of resources.</p> <p>CCGs are already required to make arrangements so that individuals for whom services are being or may be provided are involved in the planning of the commissioning and any changes in the services delivered. To do this effectively local systems need to engage effectively with people who have a learning disability and their families and carers, who are representative of their local population.</p> <p>Local ICSs will need to ensure that they are supported by local organisations to share information with groups that are not well connected with services, including people from minority ethnic communities, in a range of accessible ways.</p> <p>We have commissioned Learning Disability England to develop and strengthen self-advocacy and carer support for people with a learning disability and their families from minority ethnic communities.</p>
5.	Local systems, including commissioning, to be responsive and develop strategic plans that address the longstanding needs of people with learning disabilities and their families that the COVID-19 pandemic has illuminated, including the availability of specialist learning disability teams in acute, primary and community care.	ICSs	<p>We agree that it is crucial that local systems understand the causes and impact of health inequalities for people with a learning disability in their local area and take action to tackle them.</p> <p>The new LeDeR policy requires ICSs to submit quarterly reports on Action from Learning to NHS England and NHS Improvement regional teams for monitoring and assurance. ICSs will be required to demonstrate that they have a robust process in place for ensuring that the learning from local LeDeR reviews leads to prompt and effective actions to improve care, reduce health inequalities and prevent premature mortality for people with a learning disability.</p>

No.	University of Bristol recommendation	Audience	Proposed action by NHS England and NHS Improvement
6.	<p>From the outset of any future public health emergency, the needs and circumstances of people with learning disabilities must be considered and built into national policy and guidance by the National Institute for Health Protection and the Department of Health and Social Care. A data collection tool should be established to capture emerging evidence relating to people with learning disabilities, which would trigger adjustments to policy, guidance, systems and processes as required.</p>	<p>National Institute for Health Protection, Department of Health and Social Care, NHS England and NHS Improvement</p>	<p>NHS England and NHS Improvement support the development of this data collection tool by DHSC and the successor to PHE.</p>
7.	<p>Commissioning guidance for NHS 111 services to include a requirement for the provision of specifically tailored training to NHS 111 staff about how to respond appropriately to calls about people with a learning disability or from people with a learning disability and their families.</p>	<p>NHS England and NHS Improvement</p>	<p>We are working to improve the quality of 111 services offered to people with a learning disability and autistic people.</p> <p>We will include appropriate training for NHS 111/integrated urgent care staff on how to respond to calls from or about people with a learning disability, as a requirement in the national integrated urgent care service specification for NHS 111 commissioners to implement via their individual contracts. This will include training on the provision of reasonable adjustments.</p>
8.	<p>A LeDeR representative should routinely and as of right be involved with the child death review meeting/process for children with learning disabilities, in order to ensure that necessary information is collected and transferred into the wider LeDeR programme.</p>	<p>NHS England and NHS Improvement</p>	<p>NHS England and NHS Improvement are committed to learning from the deaths of children and young people with a learning disability as well as the deaths of adults.</p> <p>We are working with the Child Death Review (CDR) programme to develop standard guidance on how information should be shared between the LeDeR and CDR programmes, to avoid duplication and address any gaps in the information currently collected, to ensure that there is effective learning from the deaths of children with a learning disability.</p>

No.	University of Bristol recommendation	Audience	Proposed action by NHS England and NHS Improvement
9.	<p>NHS England to collect and collate evidence about the needs and circumstances of people who have been subject to mental health or criminal justice restrictions and use this to inform appropriate, personalised service provision for this group of people. While waiting for this evidence, robust after-care support (as required by S117 of the Mental Health Act) must be provided.</p>	<p>NHS England and NHS Improvement, local authorities</p>	<p>NHS England and NHS Improvement welcome this important insight into the health inequalities of people who have been subject to mental health restrictions or the criminal justice system.</p> <p>We will introduce a requirement for a focused LeDeR review to be completed for all deaths of people who were subject to mental health or criminal justice restrictions at the time of their death or within the previous five years, where this information is known.</p> <p>ICs will be required to report on learning and actions taken in relation to such deaths in the quarterly reports on Action from Learning they submit to NHS England and NHS Improvement regional teams for monitoring and assurance.</p> <p>We will undertake focused work to ensure that people currently subject to mental health or criminal justice restrictions, or within the past five years, are risk stratified and prioritised for an annual health check and health action plan.</p> <p>We will review the physical healthcare questions in Care, Education and Treatment Reviews (CETRs) to ensure that people accessing CETRs have high quality physical healthcare plans in place that are regularly reviewed.</p>
10.	<p>Progress on actions in response to previous recommendations about minimising the risk of aspiration pneumonia in people with learning disabilities needs to be published.</p>	<p>NICE, Department of Health and Social Care, NHS England and NHS Improvement</p>	<p>NHS England and NHS Improvement recognise that respiratory conditions are the most significant cause of premature mortality for people with a learning disability.</p> <p>In 2020 we commissioned a toolkit and guidance from the British Thoracic Society around the prevention and treatment of pneumonia and aspiration pneumonia. This work was delayed because it required input from respiratory medicine experts who were working on the frontline in response to the COVID-19 pandemic. It has now restarted, including by convening a co-production group, and is due to be completed by spring 2022.</p>

Publication approval reference: PAR550

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

Publication date: June 2021