Learning from lives and deaths - People with a learning disability and autistic people (LeDeR): **Action from learning report 2021/22**

**Supporting resources**
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Introduction

This document accompanies the LeDeR Action from Learning report 2021/22 which provides NHS England’s response to the 2021 LeDeR Annual Report and updates on progress since last year’s Action from Learning Report. This can be found on the NHS LeDeR website.

LeDeR is a service improvement programme which aims to improve care, reduce health inequalities and prevent premature mortality of people with a learning disability and autistic people by reviewing information about the health and social care support people received. An essential part of this work is to share the learning from the reviews which have happened throughout the year and the positive practice, resources and materials needed to achieve this.

This document contains links to a range of resources which will support local systems to understand the wider context of their action from learning, to make improvement and to share good practice. It includes guidance from our national partners, including those which describe the required standards for providing and monitoring care, and examples and links to resources created by services and their partners through action from learning.

This is not an exhaustive list of guidance and we have not included the many examples of positive practice we have received from across England in this document.

NHS England cannot be held responsible for the content of external links.
National guidance, policy and quality standards

The NHS Long Term Plan
www.longtermplan.nhs.uk
The NHS Long Term Plan (2019) explains the ambitious improvements in care we want to see for patients over the next ten years and sets out how we can overcome the challenges the NHS faces. Click for the easy read version.

Learning from lives and deaths (LeDeR) Policy
The new LeDeR policy set out for the first time for the NHS the core aims and values of the LeDeR programme and the expectations placed on different parts of the health and social care system in delivering the programme from June 2021.

The NHS Operational Planning and Contracting Guidance 2022/23
www.england.nhs.uk/operational-planning-and-contracting
This guidance covers system planning, full operational plan and workforce transformation requirements, the financial settlement and the process and timescales for submitting plans, including LeDeR, that are needed to meet NHS priorities for 2022/3.

NHS Patient Safety Strategy
This describes how the NHS will continuously improve patient safety, building on the foundations of a safer culture and safer systems. Includes easy read version.

Ask Listen Do – NHS England
www.england.nhs.uk/learning-disabilities/about/ask-listen-do
This supports organisations to learn from, and improve the experiences of people with a learning disability and/or people who are autistic or both, and their families and carers when giving feedback, raising a concern or making a complaint. It also makes it easier for people, families and paid carers to give feedback, raise concerns and complain.

We are the NHS: People Plan
www.england.nhs.uk/ournhspeople
‘More people, working differently, in a compassionate and inclusive culture.’
This ambition and the NHS People Plan sets out actions to support transformation across the whole NHS. It focuses on how we must all continue to look after each other and foster a culture of inclusion and belonging, as well as action to grow our workforce, train our people, and work together differently to deliver patient care.
Reasonable Adjustments – Guidance


Information and guidance on making reasonable adjustments. Organised by health subject area, from Annual Health Checks to substance misuse, this is aimed at health and social care professionals and family members/carers who support and plan care for people with a learning disability. Each topic also has an easy read version.

NICE Guidelines: Learning Disability

www.nice.org.uk/guidance/population-groups/people-with-learning-disabilities

Quality standards for the care and support for children, young people and adults with a learning disability.

E-Learning for Healthcare professionals – the All Our Health programme

www.e-lfh.org.uk/programmes/all-our-health

Health Education England's e-learning for healthcare platform aims to give health and social care professionals more confidence and skills to make prevention, staying well and promoting wellbeing a part of their everyday practice.

NHS Digital and NHS England

https://digital.nhs.uk/services/reasonable-adjustment-flag

The Reasonable Adjustment Flag is a national record which indicates that reasonable adjustments are required for an individual and optionally includes details of their significant impairments and key adjustments that should be considered. The reasonable adjustment flag has been successfully piloted and is in the final stages of development.

Reports

LeDeR Action from Learning reports - NHS England

https://leder.nhs.uk/resources/action-from-learning-reports

We use the insights we gather from the LeDeR reviews to improve the health of people with a learning disability. It also helps us to reduce health inequalities.

Action from learning reports provide examples of changes that we have made to services so far. They show the work we are doing across the country to respond to common themes raised through LeDeR reviews.

University of Bristol – LeDeR Programme Annual Reports (until 2021)

www.bristol.ac.uk/sps/leder/uob-2015-21/annual-reports

The LeDeR Annual Report was produced for NHS England and by the University of Bristol until 31 May 2021. Each year it published an annual report about its findings over the past calendar year. All previous reports can be found on its website.
Data

**NHS Digital: Health and Care of People with Learning Disabilities Standardised Mortality Ratio Indicator**
This three-year rolling indicator provides the ratio of deaths among people with a learning disability to the number of expected deaths, compared with that of the general population. It contributes to an understanding of the impact of changes in care to address premature mortality.

**Office for Health Improvement and Disparities: Learning Disability Profiles**
https://fingertips.phe.org.uk/profile/learning-disabilities
The ‘fingertips profile’ for people with a learning disability includes tools and data for professionals to help with planning and reduce health inequalities.

**Child Outcomes Research Consortium (CORC)**
CORC’s resource hub for professionals working with children and young people with a learning disability includes guidance and tools to support the development and use of outcome measures and feedback.

**Mencap: Research and statistics**
www.mencap.org.uk/learning-disability-explained/research-and-statistics
Mencap, a charity which supports people with a learning disability, and their families and carers, has the latest statistics on a range of issues affecting people with a learning disability – from health and social care to finding work and friendships.

Respiratory health

**NHS England - Flu toolkit**
National Public Health England flu campaign and the National NHS winter pressures campaign – toolkit published in winter 2021 for health and social care organisations to use with people with a learning disability to increase uptake of the flu vaccine.
NICE Guideline: Flu vaccination – increasing uptake
www.nice.org.uk/guidance/ng103
This guideline covers how to increase uptake of the free flu vaccination among people who are eligible. It describes ways to increase awareness and how to use all opportunities in primary and secondary care to identify people who should be encouraged to have the vaccination.

NHS: Flu vaccination – an easy read
An easy read flu leaflet with information for people with a learning disability on protection from flu and reasonable adjustments that can be made e.g. for anyone who is needle-phobic.

NICE – Guideline: Pneumonia in adults: diagnosis and management
www.rcplondon.ac.uk/guidelines-policy/pneumonia-adults-diagnosis-and-management-nice-guideline
This National Institute for Health and Care Excellence (NICE) guideline covers diagnosing and managing community and hospital-acquired pneumonia in adults. It aims to improve accurate assessment and diagnosis of pneumonia to help guide antibiotic prescribing and ensure that people receive the right treatment.

Cancer

Northern Cancer Alliance: Promoting access to cancer screening for people with a learning disability
Cancer screening information pack which includes information on capacity and consent, best interest guidance, easy read invitation letters for GPs, sample letters for parents and carers and links to national easy read materials.

PHE – Screening inequalities strategy
Guidance to support the health system to reduce inequalities in screening.

Beyond Words – picture stories on cancer screening
https://phescreening.blog.gov.uk/2021/05/19/pioneering-picture-stories-can-help-reduce-barriers-to-nhs-cancer-screening
Pioneering charity Beyond Words has updated its wordless picture stories about bowel cancer screening, breast screening and cervical screening.
PHE: Cancer screening: Making reasonable adjustments
Guidance for health and social care professionals and family members/carers, on reasonable adjustments before and during cancer screening – including an easy read version.

PHE: Cervical screening: supporting women with a learning disability
Information, resources and guidance for healthcare professionals on supporting women with a learning disability to access cervical screening (Last updated 2019) with easy read invitation letter template.

PHE: Breast screening: easy guide
Information, resources and guidance for healthcare professionals on supporting women with a learning disability to access breast screening.

Mencap: Bowel cancer screening: having a colonoscopy – an easy guide
An easy read guide to having a colonoscopy from the NHS, hosted by Mencap.

PHE: Bowel cancer screening: an easy guide to having a CTC scan
Bowel cancer screening: an easy read guide to having a CTC scan.

PHE: Bowel cancer screening: helping people with learning disabilities
Information, resources and guidance for healthcare professionals on supporting people with a learning disability to access bowel cancer screening (Updated Dec 2021), including easy read materials and short films.

Cancer red flag symptoms by People First Merseyside
www.youtube.com/watch?v=2ve16vQ4UGE
The ‘red flag’ symptom awareness campaign and film by People First Merseyside was created to raise awareness of red flag symptoms of cancer for people with a learning disability.
Sepsis and deterioration

NHS England: Easy read information: Sepsis
www.england.nhs.uk/publication/easy-read-information-sepsis
Easy read information about how to avoid sepsis, spotting the signs of sepsis, and problems after sepsis.

Health Education England (HEE) – Resources on sepsis
www.youtube.com/watch?v=LlZk9A6bBWw
A film giving more details on a series of training films about sepsis and managing deterioration for clinical staff and others including those in paediatric settings.

www.e-lfh.org.uk/programmes/sepsis/ - ‘THINK SEPSIS’ is a HEE programme aimed at improving the diagnosis and management of those with sepsis.


Sepsis Trust
https://sepsistrust.org/professional-resources/education-resources
Short films and guidance for professionals about sepsis and how to identify it – includes a sepsis manual and educational videos.

East and North Hertfordshire NHS Trust and Hertfordshire County Council
Easy read signs of sepsis information leaflet from East and North Hertfordshire NHS Trust.

Purple All Stars – Check me for sepsis
www.youtube.com/watch?v=FZq5sYulOB8
Purple All Stars (a creative arts group of people with a learning disability) has produced a song and video about sepsis which aims to educate people with a learning disability and the people who support them, to know what sepsis is and when someone has possible signs to remember to ask the health professionals, ‘Is it sepsis?’

Constipation

Books Beyond words – The Trouble with Poo
https://booksbeyondwords.co.uk/bookshop/trouble-with-poo
The Trouble with Poo is a story book to make conversations about constipation easier. It describes how a healthy diet, drinking fluid and taking exercise are important and when to seek help. Available as paperback and e-book.
NHS England – constipation resources
www.england.nhs.uk/publication/constipation-learning-disability-resources
Information for people with a learning disability, their families and carers and healthcare professionals about the signs of constipation and what to do about it.

NICE: Clinical guidelines – Faecal incontinence in adults: management
www.nice.org.uk/guidance/cg49
This guideline covers assessing and managing faecal incontinence (any involuntary loss of faeces) in people aged 18 and over. It aims to ensure that staff are aware that faecal incontinence is a sign or a symptom, not a diagnosis.

NICE: Quality standards – Faecal incontinence in adults
www.nice.org.uk/guidance/qs54
This quality standard covers managing faecal (bowel) incontinence in adults (aged 18 and over) in the community (at home and in care homes) and in all hospital departments. It includes assessment of bowel control problems, advice and support, and treatment options. It describes high-quality care in priority areas for improvement.

Epilepsy

NHS England: Epilepsy toolkit
www.england.nhs.uk/rightcare/products/pathways/epilepsy-toolkit
NHS RightCare toolkit for epilepsy was developed in partnership with Epilepsy Action, SUDEP Action and Young Epilepsy to help systems, commissioners and services understand the priorities for epilepsy care and what action is needed to address them.

NICE: Quality Standard - Epilepsy in children and young people
www.nice.org.uk/guidance/qs27
This quality standard covers diagnosing, treating and managing epilepsy and seizures in children and young people (under 18). It describes high-quality care in priority areas for improvement.

NICE: Quality Standard - Epilepsy in adults
www.nice.org.uk/guidance/qs26
This quality standard covers diagnosing, treating and managing epilepsy and seizures in adults (aged 18 and older). It describes high-quality care in priority areas for improvement.
NICE: Clinical Guideline: Epilepsies: diagnosis and management
[link](www.nice.org.uk/guidance/cg137)
The guideline covers diagnosing, treating and managing epilepsy and seizures in children, young people and adults in primary and secondary care. It offers best practice advice on managing epilepsy to improve health outcomes so that people with epilepsy can fully participate in daily life. It also includes an MHRA update on some antiepileptic medications (Updated May 2021).

SUDEP (Sudden Unexpected Death in Epilepsy) Action
[link](https://sudep.org/article/new-sudep-action-project-My-Life-With-Epilepsy)
My Life with Epilepsy is a project led by SUDEP Action, working with Speakup, Cornwall Partnership NHS Foundation Trust, University of Plymouth’s Peninsula School of Medicine, and University of Sheffield’s School of Education. It will be improving and developing information and resources to help people with a learning disability and autistic people to better understand and reduce their epilepsy risks.

WHO: Epilepsy: a public health imperative
[link](www.who.int/publications/i/item/epilepsy-a-public-health-imperative)
This 2019 report was the first global report on epilepsy summarising the available evidence on the burden of epilepsy and the public health response required at global, regional and national levels.

Diabetes

Diabetes UK: Improving care for people with diabetes and a learning disability
[link](www.diabetes.org.uk/professionals/resources/shared-practice/for-people-with-learning-disability)
This is a collection of resources and tools for professionals to improve care for people with a learning disability. Includes easy read information.

NHS RightCare – Diabetes pathway
[link](www.england.nhs.uk/rightcare/products/pathways/diabetes-pathway)
Guidance on reasonable adjustments for people with a learning disability who have diabetes is part of the NHS RightCare pathway and supports commissioners and providers to improve diagnosis and management of care for people with a learning disability.
Oral care

**NICE - Guidelines: Oral health for adults in care homes.**
[www.nice.org.uk/guidance/ng48](http://www.nice.org.uk/guidance/ng48)
This guideline covers oral health, including dental health and daily mouth care, for adults in care homes. The aim is to maintain and improve their oral health and ensure timely access to dental treatment.

**PHE: Oral care and people with learning disabilities**
Guidance to help health professionals, paid social care staff and family members to support someone with a learning disability to get good oral care.

**Oral Health Foundation – Dental care for people with special needs**
Information from the Oral Health Foundation includes guidance on helping someone with a learning disability to access dental care, oral care for people with a learning disability and information about common procedures. It also has a free and confidential helpline for advice: 01788 539780.

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**Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)**

**Learning Disability England: DNR: A guide for understanding your rights and challenging decisions**
Guide is to help people with a learning disability, their families and support staff understand DNRs.

**Care Quality Commission (CQC) – Protect, respect, connect**
The CQC’s review of ‘do not attempt cardiopulmonary resuscitation’ decisions during the coronavirus (COVID-19) pandemic.
Mental Capacity

**NICE: Guideline – Decision making and mental capacity**
www.nice.org.uk/guidance/ng108
This guideline covers decision-making in people aged 16 years and over who may lack capacity now or in the future. It aims to help health and social care practitioners support people to make their own decisions where they have the capacity to do so. It also helps practitioners to keep people who lack capacity at the centre of the decision-making process.

**NHS – The Mental Capacity Act (MCA)**
www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act
NHS information about the Mental Capacity Act.

**Mencap: Mental Capacity Act: Information and resource pack**
www.mencap.org.uk/advice-and-support/mental-capacity-act
Mencap’s Mental Capacity Act resource pack for family carers of people with a learning disability explains in detail the purpose of the act, how and when it applies to someone’s care, what it means for decision making, where to get more information and what to do if you have complaints and concerns.

**NHS Commissioning**

**NHS Standard Contract 2022/23 – All documents for commissioners**
www.england.nhs.uk/nhs-standard-contract
The NHS Standard Contract Particulars, Service Conditions and General Conditions which are applicable to contracts between 1 April 2022 and 31 March 2023.

**NHS Standard Contract 2022/23 – Technical Guidance**
The Contract Technical Guidance is intended to support commissioners in using the NHS Standard Contract and sets out clear expectations for how certain aspects should be addressed.

**NHS England: Commissioning – key documents**
www.england.nhs.uk/commissioning/spec-services/key-docs
This national service model (also available in easy read) is supported by supplementary guidance for commissioners and describes what good services should look like. There are also three model service specifications, also available in easy read which explain to commissioners the specialist support.
NHS England: The learning disability improvement standards for NHS Trusts
www.england.nhs.uk/learning-disabilities/about/resources/the-learning-disability-improvement-standards-for-nhs-trusts
We have developed new standards to help NHS trusts measure the quality of care they provide to people with learning disabilities, autism or both.

Annual Health Checks (AHCs)

NHS England: Annual Health Checks
www.england.nhs.uk/learning-disabilities/improving-health/annual-health-checks
People with a learning disability often have poorer physical and mental health than other people. An annual health check can improve people’s health by spotting problems earlier. This site includes an easy read letter on AHCs, a series of good examples across English regions of AHCs, and details of the national health check template.

ACE Anglia – AHC peer health educator network
www.aceanglia.com/what-we-do/peer-educator-networks/the-ld-annual-health-check-peer-educator-network
The Learning Disability Annual Health Check Peer Educator Network at self-advocacy charity Ace Anglia has published its education workshop materials online including a video, top tips and worksheets to help people with a learning disability understand the need for AHCs including details of what happens during an AHC.

Contact – information for parents on AHCs
Their website include a factsheet to help parents ensure their young person is on the learning disability register and has an annual health check. It also has two co-produced resources for health professionals.

Mencap – Joining the learning disability register
www.mencap.org.uk/advice-and-support/health/dont-miss-out
Mencap’s Don’t Miss Out resources explain the benefits of the learning disability register and an annual health check. Materials include easy read guides, an introductory video and a short film in which people with a learning disability talk about the benefits of health checks, as well as information for healthcare professionals.
Guidance for general practice explains how GPs should update their registers to make sure eligible patients are flagged for a health check, under the Quality Outcomes Framework (QOF) programme.

NHS England – Update on Quality Outcomes Framework 2022/23
Document providing details of the updated Quality Outcomes Framework for General Practice.

Hospital – admission and discharge

NHS – Support if you are going in to hospital
www.nhs.uk/conditions/learning-disabilities-going-into-hospital
Information and links to resources about going into hospital to help people with a learning disability as well as families and carers. The information explains the role of learning disability nurses, consent and capacity - and the site includes a video for NHS staff made by people with lived experience, explaining the importance of reasonable adjustments.

My hospital visit – Information to take home – an easy read.
http://s3-eu-west-1.amazonaws.com/files.royalfree.nhs.uk/Safeguarding/(Final)_My_hospital_visit_-_information_to_take_home.pdf
Enfield’s integrated learning disability service (a partnership between local authority and health services) created an easy read discharge booklet, ‘My hospital visit – information to take home’ so that people with a learning disability have the information they need about their treatment and can share that with others involved in their care. It is used at the Royal Free London Hospitals.

EasyHealth - Health information with simple words, clear pictures and films
www.easyhealth.org.uk
EasyHealth has a range of easy read materials, leaflets and films in its online library to support people with a learning disability and others who need hospital treatment, either as an inpatient or for outpatient care. The resources also include materials about a range of health conditions and treatments – from asthma to x-rays.
Reasonable adjustments

UK legislation: The Equality Act
The Equality Act (2010) legally protects people from discrimination in the workplace and in wider society. It replaced previous anti-discrimination laws with a single Act, making the law easier to understand and strengthening protection in some situations. Section 20 covers the duty to make reasonable adjustments for people with relevant ‘protected characteristics.’

NHS England – Reasonable adjustments guidance and resources for clinicians and non-clinicians
www.england.nhs.uk/learning-disabilities/improving-health/reasonable-adjustments/
An explanation of reasonable adjustments, along with resources to support someone having a COVID-19 vaccination or booster.

COVID-19

NICE – COVID-19 rapid guideline: Managing COVID-19 (Updated March 2022)
www.nice.org.uk/guidance/ng191
This guideline covers the management of COVID-19 for children, young people and adults in all care settings. It brings together the NICE existing recommendations on managing COVID-19, and new recommendations on therapeutics, so that healthcare staff and those planning and delivering services can find and use them more easily.

NHS England - Action from learning: deaths of people with a learning disability from COVID-19
In November 2020 the University of Bristol published its report into the deaths of 206 people with a learning disability at the start of the COVID-19 pandemic. This report highlighted some good practice in the care of people with a learning disability, but it also highlighted concerns about the care that some people received. The above LeDeR report outlined the actions that the NHS worked with system partners to implement.
Public Health England – Research and analysis on COVID-19 deaths
The Department of Health and Social Care, with the support of the Chief Medical Officer for England, commissioned PHE to review the available data on the deaths of people with learning a disability in England during the coronavirus (COVID-19) pandemic – from the start of the pandemic to 5 June 2020.

NHS England – ‘Grab and Go’ guide
A COVID specific ‘Grab and Go’ form for people with a learning disability or who are autistic who are hospitalised with COVID-19. The form includes details on communication, usual medications, previous conditions and more. It can be used in tandem with a hospital passport form.

NHS England – Grab and Go guidance
A ‘Grab and Go’ guide for people who are hospitalised with COVID-19 was designed in partnership with people with a learning disability, families and nurses. This does not replace a hospital passport.

End of life care

MacIntyre
www.macintyrecharity.org/our-approach/resources/life-story-wellbeing-for-life/
Useful information and resources on how to create life stories for people with dementia and a learning disability - from the charity MacIntyre.

Marie Curie – palliative care for people with a learning disability
This guidance is for healthcare professionals on understanding a person’s needs and improving their quality of life in palliative care. They also have a series of easy read materials for people with a learning disability and carers caring for someone who is dying.
Delivering high quality end of life care for people who have a learning disability – NHS England
Resources and tips for commissioners, service providers and health and social care staff including an ambition to view people holistically when providing end of life care.

Palliative Care for People with Learning Disabilities Network
www.pcpld.org/links-and-resources
Resources and easy read materials about palliative care, advanced planning and bereavement support.

Cardiac care

Cardiovascular disease prevention: applying All Our Health
Guidance from the Office of Health Improvement and Disparities (OHID) for healthcare professionals on prevention of cardiovascular disease, which still remains a significant cause of disability, death and health inequalities.

All Our Health: Cardiovascular Disease Prevention
https://portal.e-lfh.org.uk/Component/Details/571421
OHID and Health Education England’s ‘e-Learning for Healthcare’ have developed this interactive e-learning content to increase the confidence and skills of health and care professionals, to embed cardiac disease prevention in their day-to-day practice.

Public Health England
Working with partners, PHE and NHS England agreed ambitions in 2019 which seek to address the A, B and C of secondary prevention and reduce the health inequalities associated with cardiovascular disease (CVD) over the next 10 years.
Integrated Care Systems

One of the lessons learned from the COVID-19 pandemic is that people need support which is joined up across local councils, the NHS and voluntary and community organisations. Integrated Care Systems aim to embed this collaboration.

**NHS England – a film explaining ICSs**  
www.youtube.com/watch?v=mz4FFE2y8PM

**NHS England – a website explaining ICSs**  
www.england.nhs.uk/integratedcare/
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This document is available in easy read and can be provided in alternative formats on request.

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