

Learning from Lives and Deaths - People with a Learning Disability and Autistic People (LeDeR)

Action from Learning 2020/21

Helpful resources

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Introduction

This document accompanies the Action from Learning report 2020/21 which provides NHS England and NHS Improvement's response to the 2020 LeDeR Annual Report and updates on progress since last year's Action from Learning Report.

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 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. We will be developing an area of our website on which more examples can be shared.

1. Useful documents and resources

1.1 Policy documents, quality standards and national guidance

NHS England and NHS Improvement - www.longtermplan.nhs.uk

The NHS Long Term Plan 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. The easy read version is here: www.longtermplan.nhs.uk/wp-content/uploads/2019/01/easy-read-long-term-plan-v2.pdf

NHS England and NHS Improvement - www.england.nhs.uk/learning-disabilities/improving-health/mortality-review

The new LeDeR policy aims to set out for the first time for the NHS the core aims and values of the LeDeR and the expectations placed on different parts of the health and social care system in delivering the programme from June 2021

NHS England and NHS Improvement - www.england.nhs.uk/operational-planning-and-contracting

The NHS Operational Planning and Contracting Guidance 2021/22 – 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 2021/22

NHS England and NHS Improvement - www.england.nhs.uk/patient-safety/the-nhs-patient-safety-strategy

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

NHS England and NHS Improvement - www.england.nhs.uk/learning-disabilities/about/ask-listen-do

Ask Listen Do 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.

NHS England and NHS Improvement - www.england.nhs.uk/publication/we-are-the-nhs-people-plan-for-2020-21-action-for-us-all

We are the NHS: People Plan for 2020/21 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 patientcare.

Public Health England (PHE) - www.gov.uk/government/collections/reasonable-adjustments-for-people-with-a-learning-disability

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 - www.nice.org.uk/guidance/qs101

Quality standard: Behaviour that challenges (with easy read version)

NICE - www.nice.org.uk/guidance/qs187

Quality standard: Care and support for people growing older (with easy read version)

NICE - www.nice.org.uk/guidance/ng96

Guideline: Care for people growing older (with easy read version)

NICE - www.nice.org.uk/guidance/ng56

Guideline: Multiple long-term conditions

NICE - www.nice.org.uk/guidance/ng142

Guideline: End of life care for people with life-limiting conditions

NICE - www.nice.org.uk/about/nice-communities/social-care/quick-guides/person-centred-future-planning

Quick guide: Future planning

NICE - www.nice.org.uk/guidance/ng150

Guideline: Supporting adult carers

NICE - www.nice.org.uk/guidance/ng27

Guidance: Transition from hospital to community or care home setting for adults with social care needs

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

All our health e-learning programme is available through Health Education England's e-learning for healthcare platform 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. Its bite-sized films include an introductory animation:

www.youtube.com/watch?time_continue=122&v=5JtV8Bz7uo&feature=emb_logo

NHS Digital and NHS England and NHS Improvement - www.digital.nhs.uk/services/reasonable-adjustment-flag

The reasonable adjustment flag will mean that if someone needs reasonable adjustments this can be flagged on their record so wherever they are treated it will be immediately visible to other services, who can then access information on what is needed.

1.2 Reports

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

The LeDeR Programme (LeDeR) was managed for NHS England and NHS Improvement by the University of Bristol until 31st 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.

NHS England and NHS Improvement - www.england.nhs.uk/publication/leder-action-from-learning-report

Action from Learning Report 2020 – this was our second report on work to translate learning into action in relation to the Learning Disability Mortality Review (LeDeR) programme between spring 2019 and summer 2020. It gives our response to the fourth annual LeDeR report and provides an update on actions from the third annual LeDeR report in 2019. An easy read version is here:

www.england.nhs.uk/wp-content/uploads/2020/07/Action-from-learning-Easy-Read.pdf

NHS England and NHS Improvement - www.england.nhs.uk/publication/leder-action-from-learning

Action from Learning Report 2019 – this was our first report on work to translate learning into action in relation to the Learning Disability Mortality Review (LeDeR) programme between spring 2018 and spring 2019. It gives our response to the third annual LeDeR report and provides an update on actions from the second annual LeDeR report in 2018.

An easy read version is here: www.england.nhs.uk/wp-content/uploads/2019/05/action-from-learning-easy-read.pdf

Department of Health and Social Care (DHSC) - www.gov.uk/government/publications/leder-third-annual-programme-report-government-response

The Government response to the fourth annual LeDeR report sets out the Government's response to each recommendation from the fourth annual LeDeR report in May 2020, and updates on the actions identified in its response to the second annual LeDeR report published in 2019. An easy read version is here: www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/865211/leder-response-easy-read.pdf

Department of Health and Social Care (DHSC) - www.gov.uk/government/publications/leder-third-annual-programme-report-government-response

The Government response to the third annual LeDeR report, which was published in February 2020, sets out the government's response to each recommendation from the third annual LeDeR report published in May 2019, and updates on the actions identified in its response to the second annual LeDeR report published in May 2018. An easy read version is here: www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/865211/leder-response-easy-read.pdf

DHSC and NHS England - www.gov.uk/government/publications/government-response-to-the-learning-disabilities-mortality-review-leder-programme-2nd-annual-report

The joint response from the Department of Health and Social Care and NHS England which was published in September 2018, sets out the governments and NHS England's response the second annual LeDeR report published in May 2018. An easy read version is here: www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/738894/easy-read-response-to-leder.pdf

1.3 Data

NHS Digital - www.digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/standardised-mortality-ratio-indicator

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.

PHE - www.fingertips.phe.org.uk/profile/learning-disabilities

The fingertips profile for learning disabilities includes tools and data for professionals to help with planning and reduce health inequalities.

Child Outcomes Research Consortium (CORC) - www.corc.uk.net/resource-hub/working-with-learning-disabilities

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.

1.4 Respiratory guidance and resources

NHS England and NHS Improvement - www.england.nhs.uk/south/wp-content/uploads/sites/6/2020/09/Flu-Comms-Toolkit-learning-disability-focus-2020-21.pdf
National Public Health England flu campaign and the National NHS winter pressures campaign – new toolkit with a learning disability focus to increase uptake of the flu vaccine.

NICE - 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.

Public Health England - www.gov.uk/government/publications/flu-leaflet-for-people-with-learning-disability
www.gov.uk/government/publications/flu-vaccination-easy-read-invitation-letter-template

An easy read flu leaflet and poster, supported the national immunisation and Stay Well This Winter campaign and raises awareness about why flu vaccination is important. A template easy read letter to invite people with a learning disability for a flu vaccine is also available.

NICE - 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.

1.5 Cancer guidance and resources

Northern Cancer Alliance - www.northerncanceralliance.nhs.uk/wp-content/uploads/2019/08/LDN_cancer_pack_2.pdf

Cancer screening information pack which includes information on capacity and consent, best interest guidance, easy read invite letters for GPs, sample letters for parents and carers and links to national easy read materials.

PHE - <https://phescreening.blog.gov.uk/2021/05/19/pioneering-picture-stories-can-help-reduce-barriers-to-nhs-cancer-screening/>

Pioneering picture stories can help reduce barriers to NHS cancer screening. They include an 'easy guide to breast screening' and an easy guide to cervical screening - both available on the Beyond Words website.

PHE - www.gov.uk/government/publications/cancer-screening-and-people-with-learning-disabilities

Cancer screening reasonable adjustments guidance for health and social care professionals and family members/carers, with an easy read version.

PHE - www.gov.uk/government/publications/cervical-screening-supporting-women-with-learning-disabilities

Information, resources and guidance for healthcare professionals on supporting women with a learning disability to access cervical screening (2017) with easy read invitation letter template.

PHE - www.gov.uk/government/publications/breast-screening-programme-supporting-women-with-learning-disabilities

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

PHE - www.gov.uk/government/publications/bowel-cancer-screening-colonoscopy-easy-guide

Bowel cancer screening: an easy read guide to having a colonoscopy.

PHE - www.gov.uk/government/publications/bowel-cancer-screening-an-easy-guide-to-having-a-ctc-scan

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

PHE - www.gov.uk/government/publications/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 (2020), including easy read materials and short films.

PHE - www.phescreening.blog.gov.uk/?s=learning+disabilities

Blog on work relevant to screening for people with a learning disability.

People First Merseyside - www.youtube.com/watch?v=2ve16vQ4UGE

The 'red flag' symptom awareness campaign by People First Merseyside was created to raise awareness of red flag symptoms of cancer for people with a learning disability.

1.6 Sepsis and deterioration guidance and resources

NHS England and NHS Improvement - 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:

- How to avoid sepsis
- Signs of sepsis and what to do
- Problems after sepsis

Health Education England (HEE) - www.youtube.com/playlist?app=desktop&list=PLrVQaAxyJE3cJ1fB9K2poc9pXn7b9WcQg

A series of training films about sepsis and managing deterioration using NEWS2 which highlights how anyone can spot these signs early. While aimed at care home workers, this resource can be used by anyone.

HEE - www.e-lfh.org.uk/programmes/sepsis/

Think sepsis e-learning programme provides training materials and advice for health and social care professionals. Resources include how to identify sepsis in people with a learning disability, people with a learning disability who have communication difficulties, and identifying sepsis in children and young people.

Sepsis Trust - www.sepsistrust.org/professional-resources/education-resources

Short films and guidance for professionals about sepsis and how to identify it – includes the sepsis six.

East and North Hertfordshire NHS Trust and Hertfordshire County Council
www.hertfordshire.gov.uk/media-library/documents/adult-social-services/learning-difficulties-and-dementia/sepsis/what-is-sepsis-easy-read.pdf

Easy read signs of sepsis information leaflet from Hertfordshire.

Purple All Stars - www.youtube.com/watch?v=FZq5sYulOB8

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

1.7 Constipation guidance and resources

Books Beyond words - www.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 and NHS Improvement - www.england.nhs.uk/publication/constipation-learning-disability-resources/

Information for people with a learning disability, their families and carers and healthcare professionals about constipation and what to do about it:

- Easy read leaflet about constipation
- Constipation leaflet for healthcare professionals
- Print ready constipation leaflet for healthcare professionals
- Constipation leaflet for families and carers
- Print ready constipation leaflet for families and carers.

NICE - www.nice.org.uk/guidance/cg49

Clinical guideline: Management of faecal incontinence in adults.

NICE - www.nice.org.uk/guidance/qs54

Quality standard: Faecal incontinence in adults.

1.8 Epilepsy guidance and resources

NHS England and NHS Improvement - 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 - www.nice.org.uk/guidance/qs27

Quality standard: Epilepsy in children and young adults.

NICE - www.nice.org.uk/guidance/qs26

Quality standard: Epilepsy in adults.

NICE - www.nice.org.uk/guidance/cg137

Clinical guideline: Diagnosis and management of epilepsies.

SUDEP (Sudden Unexpected Death in Epilepsy) Action - sudep.org/article/epilepsy-safety-tool-now-accessible-50-primary-care-clinicians-england

SUDEP Action has recently managed a collaboration which will see the SUDEP and seizure safety checklist, an epilepsy safety tool, integrated into 50% of GP practices from April 2020.

WHO report on Epilepsy - www.who.int/mental_health/neurology/epilepsy/report_2019/en/

Epilepsy: a public health imperative is 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.

1.9 Diabetes guidance and resources

Diabetes UK - www.diabetes.org.uk/professionals/resources/share_d-practice/for-people-with-learning-disability

Improving care for people with diabetes and a learning disability is a collection of resources and tools for professionals to improve care for people with a learning disability. Includes easy read information.

NHS RightCare - 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.

1.10 Oral care guidance and resources

NICE - www.nice.org.uk/guidance/ng48

Guidelines: Oral health for adults in care homes.

PHE - www.gov.uk/government/publications/oral-care-and-people-with-learning-disabilities

Guidance about oral care and dental treatment for people with learning disabilities is aimed at dental and learning disability staff as well as family and other carers helping someone with their daily oral care and with accessing dental services. Includes easy read summary.

Oral Health Foundation - www.dentalhealth.org/dental-care-for-people-with-special-needs

Information from the Oral Health Foundation includes helping someone with a 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.

1.11 Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) guidance and resources

Learning Disability England - www.learningdisabilityengland.org.uk/news/dnar-a-guide-for-understanding-your-rights-and-challenging-decisions
www.learningdisabilityengland.org.uk/wp-content/uploads/2020/06/DNACPR-Support-Pack.pdf

Guide is to help people with a learning disability, their families and support staff understand DNRs.

Care Quality Commission (CQC) - www.cqc.org.uk/publications/themed-work/protect-respect-connect-decisions-about-living-dying-well-during-covid-19

The CQC's review of 'do not attempt cardiopulmonary resuscitation' decisions during the coronavirus (COVID-19) pandemic.

1.12 Mental Capacity Act guidance and resources

NICE - www.nice.org.uk/guidance/ng108

Guidelines: Decision-making and mental capacity.

NHS - 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

www.mencap.org.uk/sites/default/files/2016-06/mental%20capacity%20act%20resource%20pack_1.pdf

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.

1.13 Commissioning guidance and resources

NHS England and NHS Improvement - www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf

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.

1.14 Annual Health Checks guidance and resources

ACE Anglia - www.aceanglia.com/resource/peer-health-educator-network/

The Learning Disability Annual Health Check Peer Educator Network at 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 annual health checks and what happens during an annual health check.

Contact - www.contact.org.uk

www.contact.org.uk/media/1525830/annual_health_checks_parents.pdf

Contact has a factsheet to help parents make sure 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:

- Making GP practices more welcoming for disabled children and their families
- Health services for disabled children.

Mencap - 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.

NHS England and NHS Improvement - www.england.nhs.uk/publication/improving-identification-of-people-with-a-learning-disability-guidance-for-general-practice

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 and NHS Improvement - www.england.nhs.uk/publication/update-on-quality-outcomes-framework-changes-for-2021-22/

Documents providing details of the updated Quality Outcomes Framework.

1.15 Guidance and resources for admission to hospital and discharge

NHS - www.nhs.uk/conditions/learning-disabilities/going-into-hospital

Information and links to resources about going into hospital are on the NHS website to help people with a learning disability as well as families and carers. The information includes reasonable adjustments, consent and the Mental Capacity Act and a video about what to take with you.

Enfield Integrated Learning Disabilities Service A2A London - [s3-eu-west-1.amazonaws.com/files.royalfree.nhs.uk/Safeguarding/\(Final\)_My_hospital_visit_-_information_to_take_home.pdf](https://s3-eu-west-1.amazonaws.com/files.royalfree.nhs.uk/Safeguarding/(Final)_My_hospital_visit_-_information_to_take_home.pdf)

Enfield's integrated learning disabilities service (a partnership between local authority and health services) created an easy read discharge booklet My hospital visit – information to take home with me 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 - www.fingertips.phe.org.uk/profile/learning-disabilities

Included in its online library, EasyHealth has a range of leaflets and helpful information to support people with a learning disability and others who need hospital treatment, either as an inpatient or for outpatient care.

1.16 Reasonable adjustments

UK legislation - www.legislation.gov.uk/ukpga/2010/15/contents

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.

1.17 Covid-19

NHS England and NHS Improvement - www.england.nhs.uk/publication/action-from-learning/

On 12 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.

Public Health England - www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities

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.

NHS England and NHS Improvement - www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0381-nhs-covid-19-grab-and-go-lda-guidance-notes.pdf

The Grab and Go guide has been designed in partnership with people with a learning disability, families and nurses. It gives the information that doctors and nurses will need if you go to hospital because of COVID-19.

NHS - www.learningdisabilityengland.org.uk/wp-content/uploads/2020/03/covid-hospital-passport.pdf

Covid-19 hospital passport.

1.18 End of life care

MacIntyre - www.macintyrecharity.org/our-expertise/resources/life-story-wellbeing-for-life/

Some useful information and resources on how to create life stories for people with dementia and a learning disability from the charity MacIntyre.

NHS England and NHS Improvement and the Palliative Care for People with Learning Disabilities Network - www.england.nhs.uk/wp-content/uploads/2017/08/delivering-end-of-life-care-for-people-with-learning-disability.pdf

Resources and tips for commissioners, service providers and health and social care staff.

Palliative Care for People with Learning Disabilities Network - www.pcpild.org/links-and-resources/

Resources and easy read resources on palliative care, advanced planning and bereavement.

1.19 Cardiac care

Public Health England - www.gov.uk/government/publications/health-matters-preventing-cardiovascular-disease/health-matters-preventing-cardiovascular-disease

Working with partners, PHE and NHS England and NHS Improvement have agreed ambitions 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.