Learning Disabilities Mortality Review
(LeDeR) Programme

NHS England

Update on Learning Disability Death Review Programme (LEDER)

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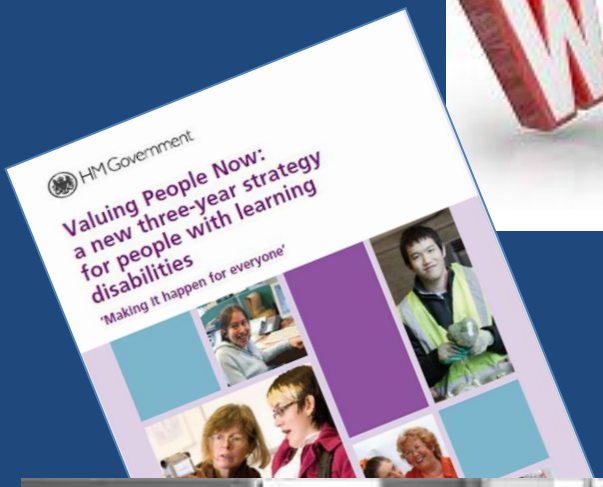
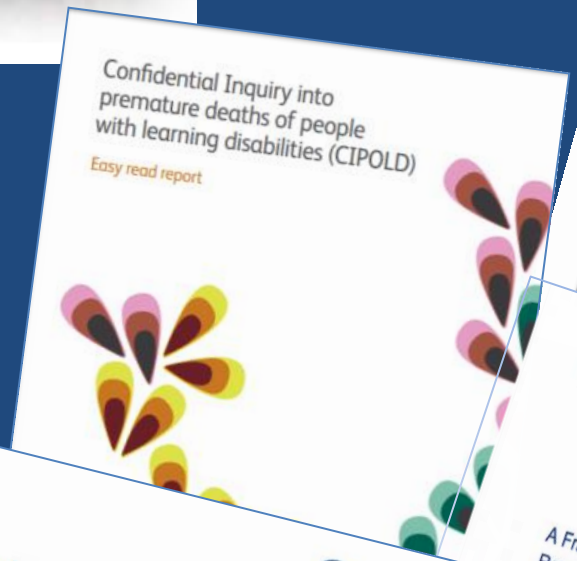
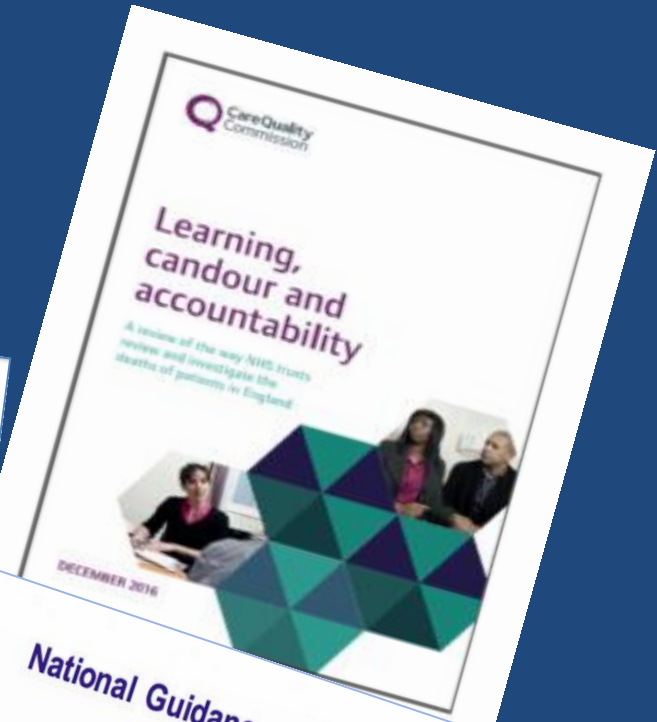
WHY?

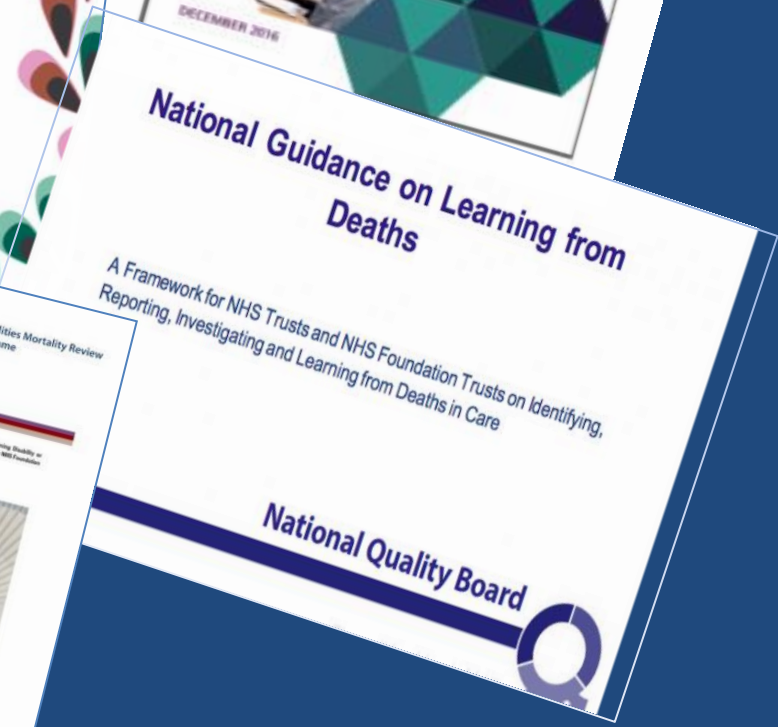

HM Government
Valuing People Now:
a new three-year strategy
for people with learning
disabilities
'Making it happen for everyone'


Confidential Inquiry into
premature deaths of people
with learning disabilities (CIPOLD)
Easy read report


CareQuality Commission
Learning, candour and accountability
DECEMBER 2016


Death by indifference
Following up the Treat me right! report
MENCAP


Background to the programme
MAZARS
Mazars Report –
An independent review of deaths of
people with a Learning Disability or
Mental Health problems in contact with
Southern Health NHS Foundation Trust
(December 2015)
Learning Disabilities Mortality Review
(LeDeR) Programme


National Guidance on Learning from Deaths
A Framework for NHS Trusts and NHS Foundation Trusts on Identifying,
Reporting, Investigating and Learning from Deaths in Care
National Quality Board

Key points about the LeDeR programme

- All deaths of people with a learning disability (age 4 years plus) to be notified to the LeDeR programme via

https://www.bris.ac.uk/sps/leder/notification-system/ or phone 0300 777 4774.

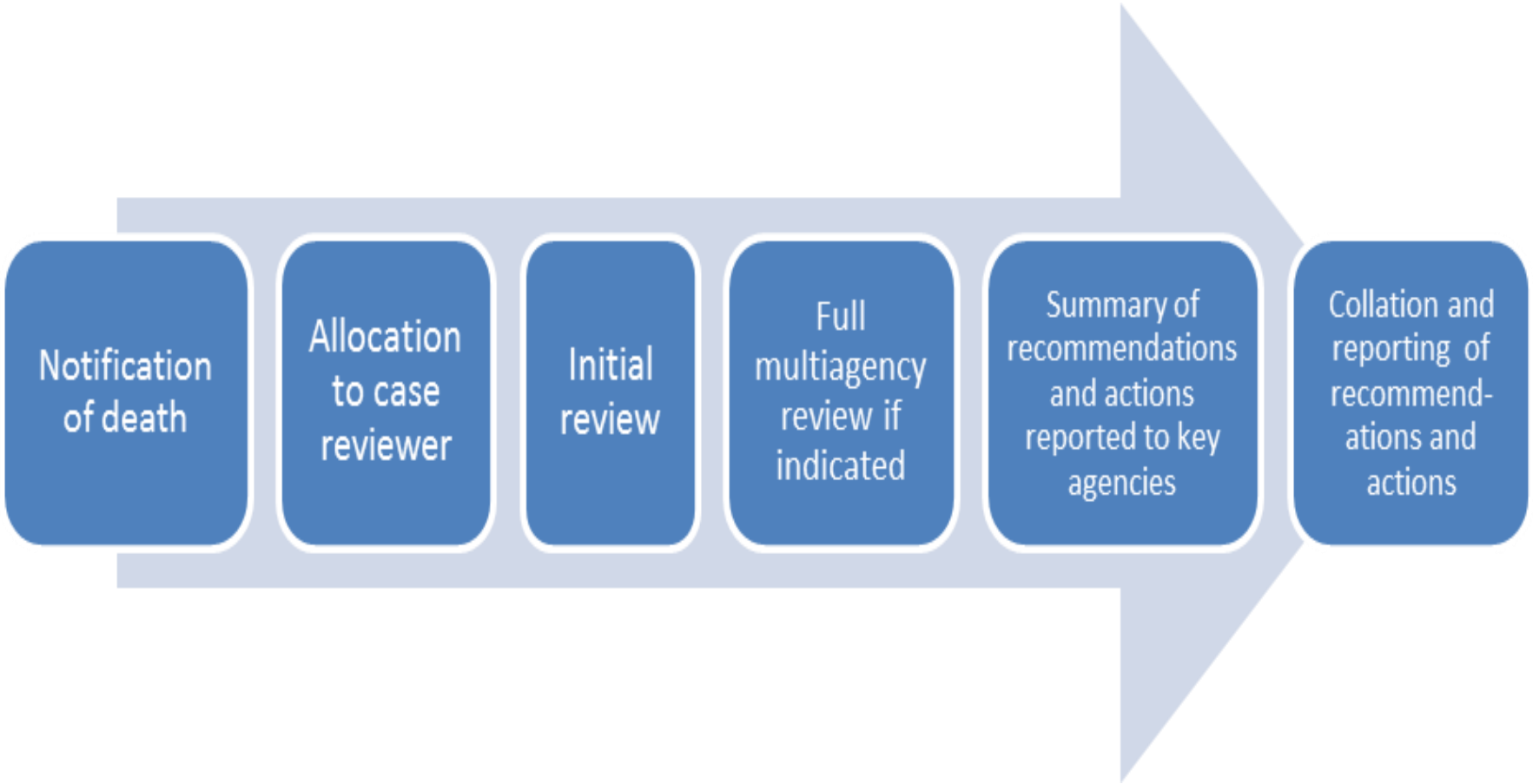
- The programme has Section 251 (NHS ACT 2006) approval to support sharing patient identifiable information across services (Ref: 16/CAG/0056)

For more information see:
https://www.hra.nhs.uk/about-us/committees-and-services/confidentiality-advisory-group/legal-frameworks/

What do we expect to achieve

- Understand further the avoidable / contributory factors to death
- Improve service delivery and health outcomes
- Reduce Health Inequalities / Discrimination
- Reduce premature death

LeDeR methodology



LEDER Review
Alice's Story

Alice

- Alice was 63 when she died
- She was a much loved sister
- Cheeky sense of humour
- Loved music
- Loved stationary
- Liked ‘dusting’!
- She had Down’s Syndrome, Alzheimer’s disease, Epilepsy & infections that kept coming back

Alice

- Alice died at home from a chest infection
- She lived with a carer for over 30 years
- ‘Match made in heaven’
- Went to a day centre 4 days a week

Important Events

- Had ‘good’ health
- Quickly deteriorated after Alzheimer’s diagnosis
- More infections

- Annual Health Check 3 years overdue

NHS
Cancer Screening Programmes

- Cancer screening overdue

What was learnt

- Good practice
- Reasonable adjustments not clearly understood
- Patchy flagging AHCs - no Health Action Plan
- Lack of advanced care planning
- Lack of understanding around MCA/BI
- Poor record keeping & communication
- Lack of referring onto specialists earlier
- Support for people after dying is poor

What We Are Doing About It?

- Increasing annual health checks
- Better invite letters, easy read information
- Cancer champions in GP
- Care Home training
- GP time out sessions
- Primary Care Macmillan team
- Health facilitation team

LEDER ANNUAL REPORT July 2016 to November 2017

What we know so far..

1311 deaths were reported to the LEDER programme

More than half were men

Most people were white

Learning From Annual Report 2017

- More people died in hospital than expected Hospital: 801 (64%)

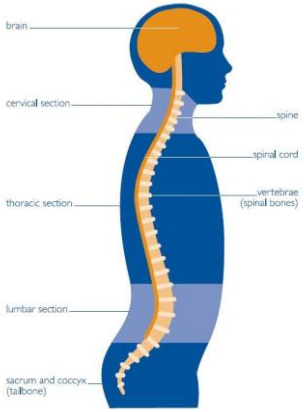
- The average age at death was 58 years old (23 & 29 years earlier than a person without a learning disability)

What are people dying from

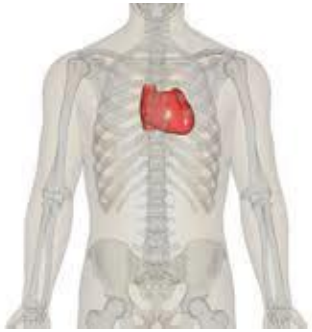
- Pneumonia
  Infection in your lungs
- Sepsis
  Infection in your body which causes damage to your organs like your heart/ kidneys
- Aspiration pneumonia
  Infection caused by food/ liquid getting into your lungs

Linked To:

Diseases of respiratory system



Diseases of Nervous system



Diseases of circulatory system

Learning & Recommendations

- Better partnership working, information sharing, and communication
- Improve understanding of the needs of people with learning disabilities
- Better understanding of the Mental Capacity Act (MCA)

Learning & Recommendations

- Named healthcare coordinators
- Identifying reasonable adjustments and recording these in patient records, checking that they help
- Increasing number of Health Action Plans, as part of Annual Health Checks

The governments response

Full support for all LEDER recommendations has been given

Public Health England

Priorities:

- How accessible information is being used to help people
- Making sure systems and guidance help people deliver good care
- Information sharing is improved between services
- Public Health England to increase flu-vaccinations

- Healthcare-coordination model is developed
- Use of Reasonable Adjustment is improved

- Mandatory learning disability awareness training

- Care Quality Commission to inspect the use of the Mental Capacity Act across services

Emerging Theme
&
Learning Examples

Providing care

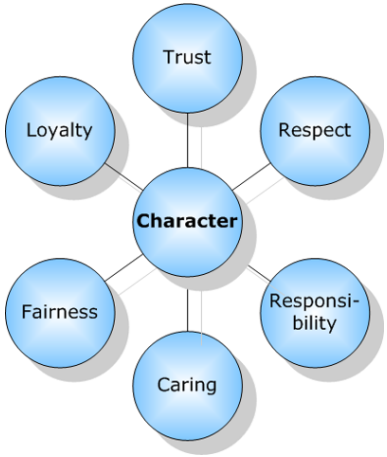
- Poor GP awareness of the causes of death or health conditions experienced by people with a learning disability

- Lack of easy read information to support communication and make sure the person had capacity and able to consent to treatment

Providing care

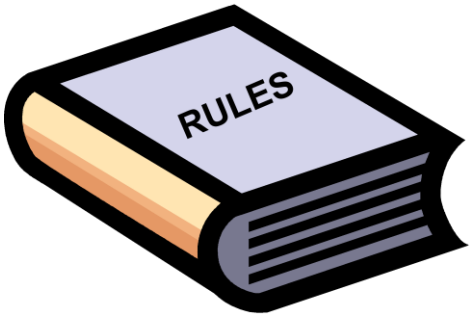
- Missed chances to prevent or reduce the risk of developing long-term conditions, such as obesity, diabetes, cardio-vascular disease. *

- Person unable to have breast screen due to needs around their mobility. *



Professional practice

- Poor practice around “Do Not Resuscitate” plans*
- Safeguarding alerts not made and only identified through LEDER review after death.
- Poor understanding of the law around reasonable adjustments.



Guidelines and the Law

- Wrong reasons/ causes recorded on death certificates. *

- Not using the Mental Capacity Act to help person get appropriate treatment

What is NHS England and LEDER doing to help

Learning Disability Mortality Review Programme

Learning into Action Group:

- Mental Capacity Act in urgent care settings
- Sepsis
- Constipation
- Pneumonia

NHS Right Care Pathways

Current work

Reasonable Adjustments standards

Diabetes pathway published

Dysphagia due to be published

Sepsis

Further work

Heart Disease

Epilepsy

Colon Cancer