Learning Disability Mortality Review Programme

NHS England Midlands and East

Learning Disabilities Mortality Review (LeDeR) Programme

NHS

Background to the programme

- Confidential Inquiry in the Deaths of people with a learning disability
- Mazars report
- Learning, Candour and Accountability
- Learning from Deaths

LeDeR programme purpose of local reviews of deaths

To help health and social care professionals and policy makers to:

- Identify the potentially avoidable contributory factors related to deaths of people with learning disabilities

- Develop action plans to make any necessary changes to health and social care service delivery for people with learning disabilities

Potentially avoidable contributory factors

The person and/or their environment

The person's care and its provision

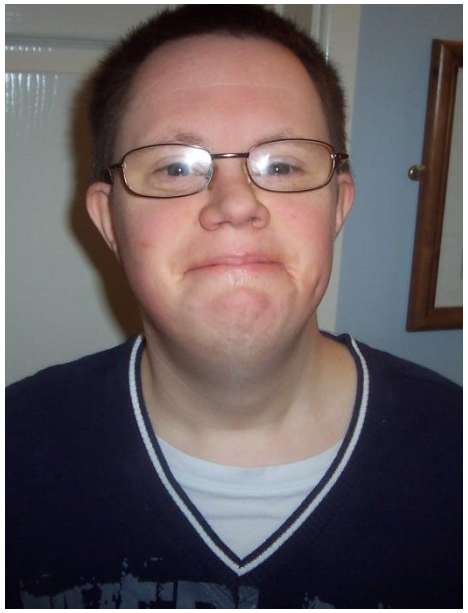
The way services are organised and accessed

Potentially Avoidable Contributory Factors

Refers to any factor:

"that has been identified as contributing to a person's death, and which, could have possibly been avoidable with the provision of good quality health or social care".

Richard Handley



Died aged 33

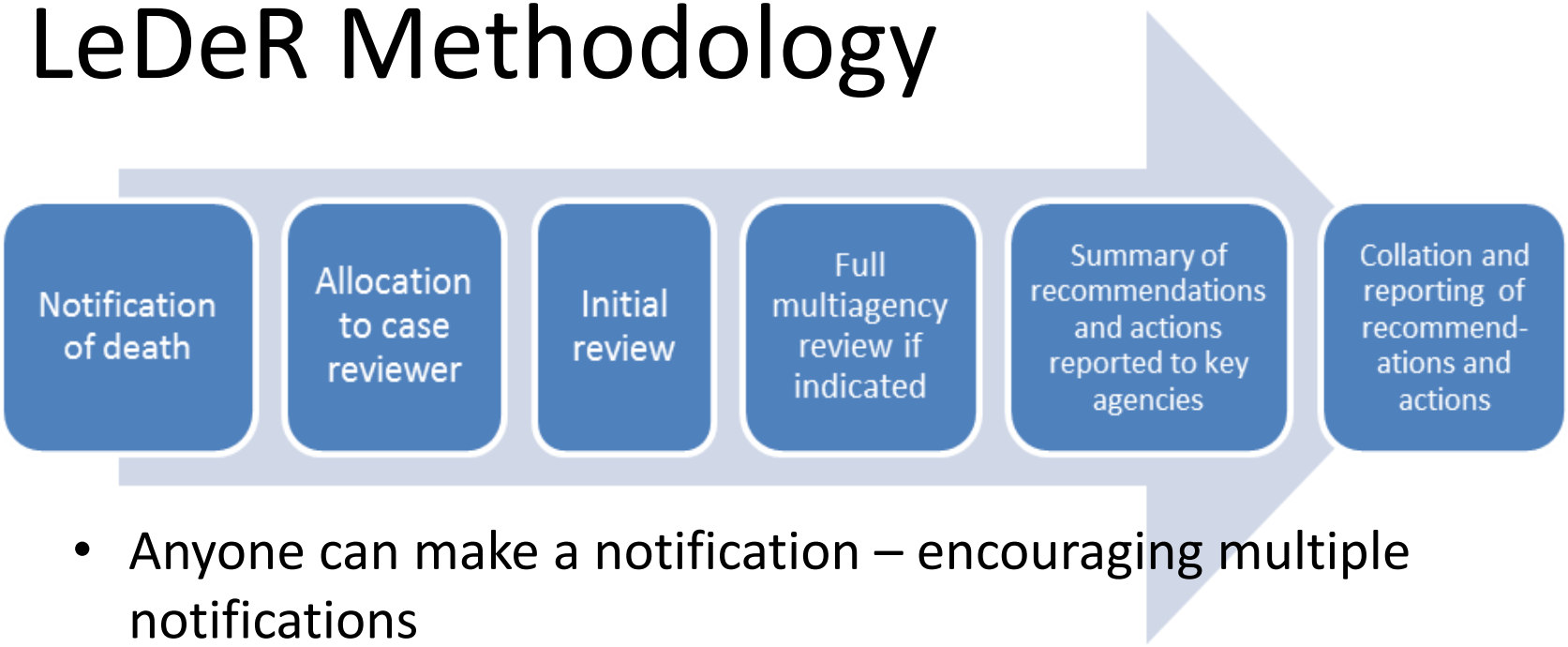
Cause of death was Aspiration Pneumonia

Chronic Constipation – 10 kg faeces removed from his bowels

Lots of missed opportunities

- Changes in registration of accommodation and support
- Poor understanding and application of the Mental Capacity Act
- Diagnostic overshadowing

LeDeR Methodology

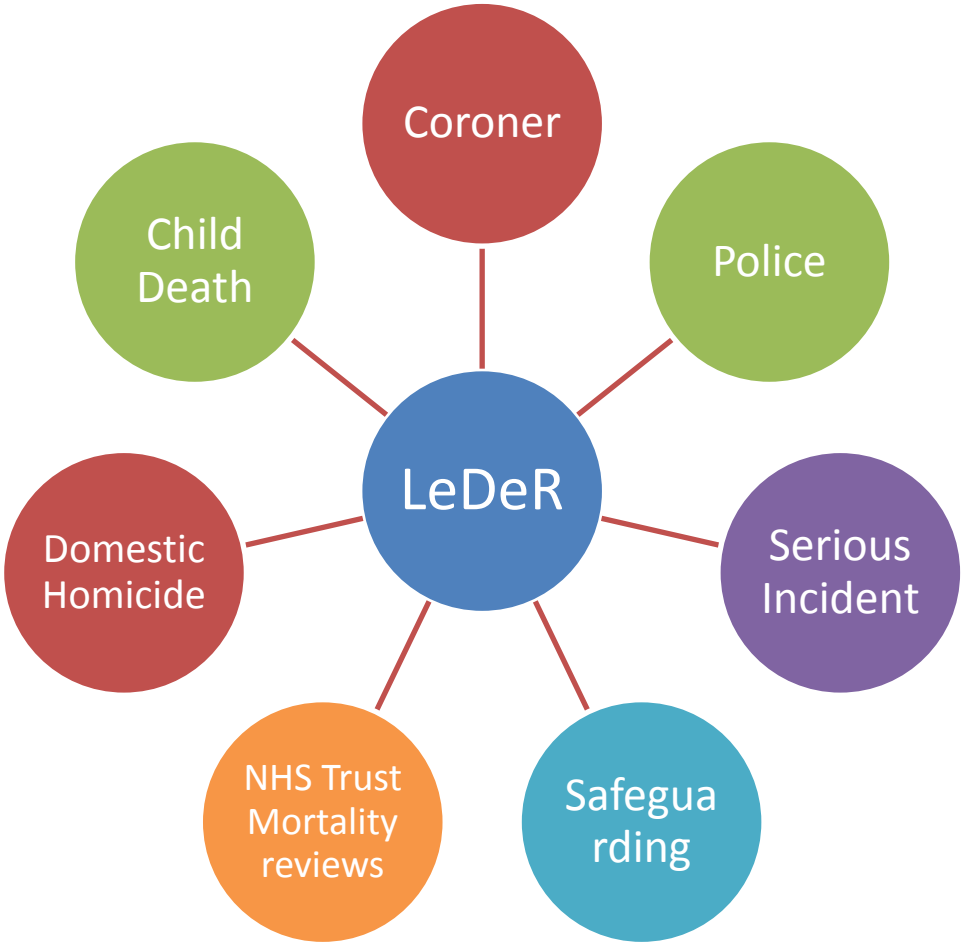


- Anyone can make a notification – encouraging multiple notifications
- Cases allocated based on location of persons registered GP
- Initial review – holistic, case notes and interview with someone who knew the person well
- Quality assurance built into process
- Steering group oversee development and delivery of action plans

How LeDeR links in to national strategies

- Planning Guidance for the NHS Standard Contract for 2018-19.
- Learning from Deaths
- CQC inspections of trusts request evidence of mortality reviews and their outcomes

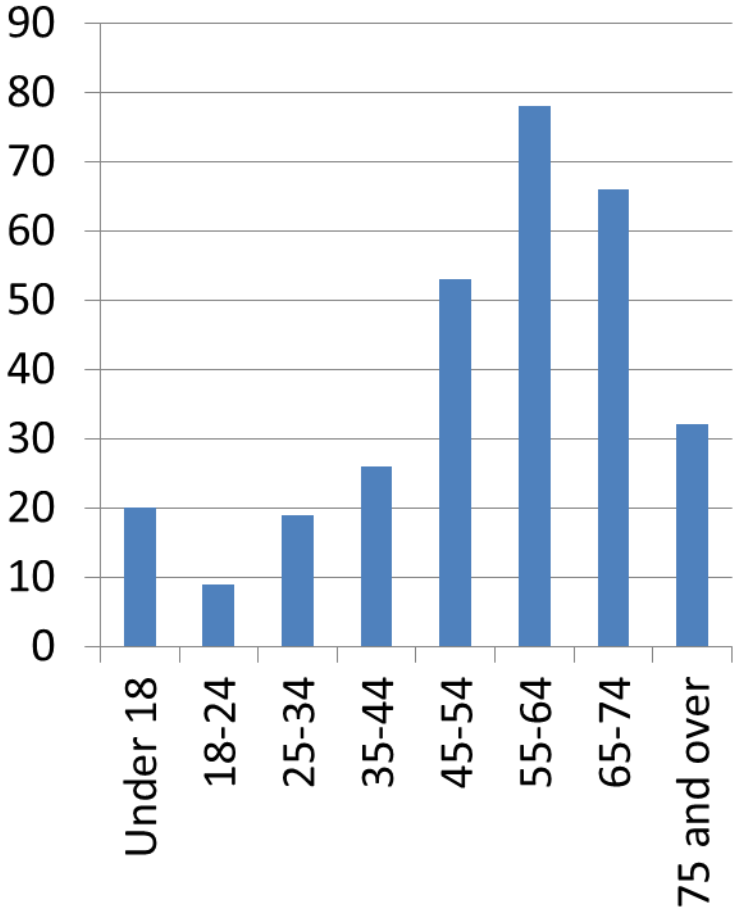
Links with other reviews and investigations



National Findings so far

- Males 57%; females 43% (n=1,311)
- White ethnic background 93% (n=1,145)
- Learning disabilities (n=828)
  - Mild learning disabilities 27%
  - Moderate learning disabilities 33%
  - Severe learning disabilities 29%
  - Profound or multiple learning disabilities 11%
- Usually lived alone 9% (n=1,158)
- Had been in an out-of-area placement 9% (n=1,158)
- Died in hospital 64%, compared with 47% in the general population (n=1,244).

Age of Death



- Median age of death is 58 (range 4-97)
  - Males – 59 years
  - Females – 56 years
- 28% of deaths were of people aged 50 and under – compared with 5% in the general population (2016)

Causes of Death

- Most common individual causes of death (n=576)
  - Pneumonia 16%
  - Sepsis 11%
  - Aspiration pneumonia 9%

Learning and Recommendations

- The most commonly reported learning and recommendations were made in relation to the need for:
  - Greater inter-agency collaboration, including communication
  - Greater awareness of the needs of people with learning disabilities
  - Greater understanding and application of the Mental Capacity Act (MCA)

Suggested targeted actions

- Identify reasonable adjustments in Summary Care Record and regularly audit their provision.
- Focus on preventative measures for pneumonia and sepsis in people with learning disabilities.
- Strengthen inter-agency collaboration, information sharing, and effective communication.
- Strengthen adherence to the Mental Capacity Act, and ensure providers of care understand its relevance to their own work setting.
- Provide mandatory learning disability awareness training to all staff.

Actions and Recommendations

- Need for improved documentation
- Learning disability Awareness
- Mental Capacity
- Annual Health Checks – checking on people who don't attend
- Hospital Passports – how are they being used, who is updating them and how many types are being used.

Thank You

www.bristol.ac.uk/sps/leder/

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