Learning Disabilities Mortality Review (LeDeR) Programme

NHS England

Safeguarding and the learning from deaths programme for people with a learning disability:

How does it work together?

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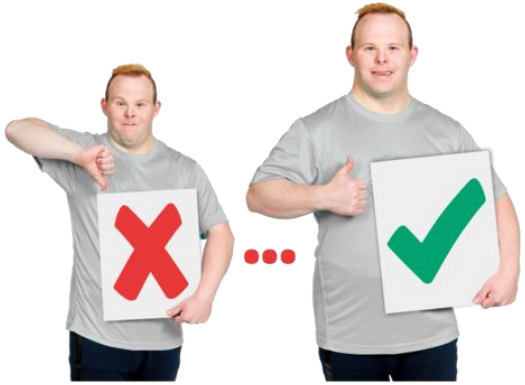
Learning Outcomes

- Awareness of LeDeR programme
- Safeguarding under-reported in people with a learning disability
- Streamlining Multiagency Review and Safeguarding Adult Review processes

Questions to hold in mind

- Why do you think safeguarding referrals are not always raised for people with a Learning Disability?
- If there is a recurrent preventable physical health condition that is not appropriately addressed when does this become safeguarding?
- How can we improve recognition of safeguarding concerns for people with a Learning Disability?
- Do you think there is a potential to better streamline the process between LeDeR and safeguarding?

The Learning Disability Mortality Review LeDeR Programme



- All deaths of people with Learning Disabilities aged 4+ require review

- Aims to reduce health inequalities & premature mortality through:
  - Sharing best practice
  - Identifying areas for improvement
  - A local responsibility to improve services via ‘action plans’ following completed reviews

LeDeR findings to date – London (Sept 2018)

- Compared with the general population, the average age of death for people with LD is:
  - 23 years younger for men
  - 29 years younger for women

- Median age of death for people with LD is:
  - 59 in England
  - 57 in London

LeDeR findings to date – Annual report (May 2018)

- 13% people's health was adversely affected by:
  - Delays in care or treatment
  - Gaps in service provision
  - Organisational dysfunction
  - Neglect or abuse.

- Place of Death:
  - Hospital: 64% (47% in gen. pop.) (65% in SEL)
  - Home: 30%
  - Hospice / palliative care unit: 2%

- Additional Investigations:
  - Post Mortems: 12%
  - Coroners Inquests: 5%
  - Other review process: 12%

Cause of Death

- Most common <u>individual causes of death</u>
  - Pneumonia 16%
  - Sepsis 11%
  - Aspiration pneumonia 9%

- Most common <u>underlying causes of death</u>
  - Diseases of respiratory system: 31%
  - Diseases of circulatory system: 16%
  - Neoplasms (cancer): 10%

Learning & Recommendations

What else do you need to put in place locally to overcome these factors?

Those most commonly reported related to the need for:

1) Greater inter-agency collaboration, including communication
2) Greater understanding and application of the Mental Capacity Act (MCA)
3) Greater awareness of the needs of people with learning disabilities

Local service change is required across health AND social care to address these familiar "lessons"

Mental Capacity Act

Issues highlighted:

- Need to **improve awareness of MCA** so it becomes central to professionals' working lives.
- Improved understanding of **when an assessment of capacity is required**.
- Greater use of an **independent advocate**.
- Improved **training** for staff about the MCA.
- Adherence to guidance on **Deprivation of Liberty Safeguards**.
- Practitioners not **communicating with family or representatives** about the care needs of people with disabilities.
- Staff and professionals unclear of the need to involve or inform family members.

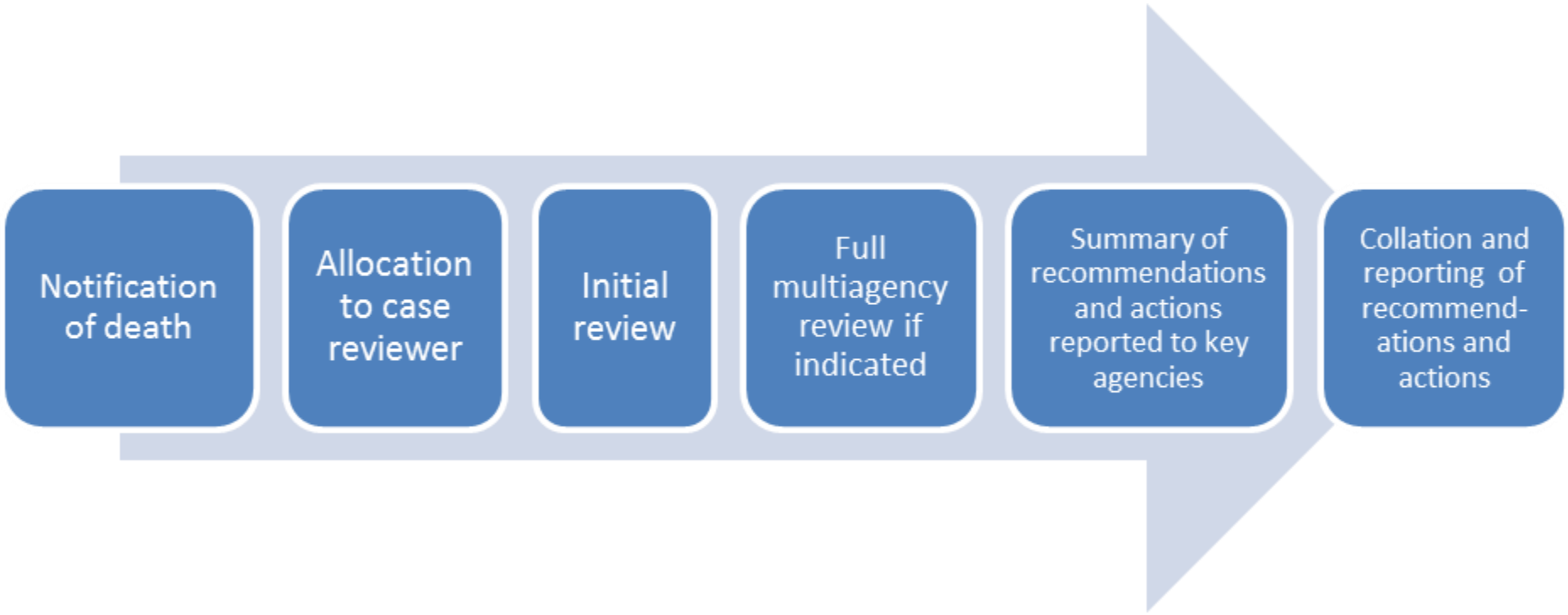
Safeguarding – what do we know?

- LeDeR reviewers are identifying safeguarding & serious incidents that were not yet reported.
- Unconscious bias/diagnostic overshadowing
- Professionals do not always recognise duty to raise safeguarding concerns
  - relating to physical healthcare
  - relating to practice of colleagues
  - after a death
- Opportunities to learn & improve services are missed

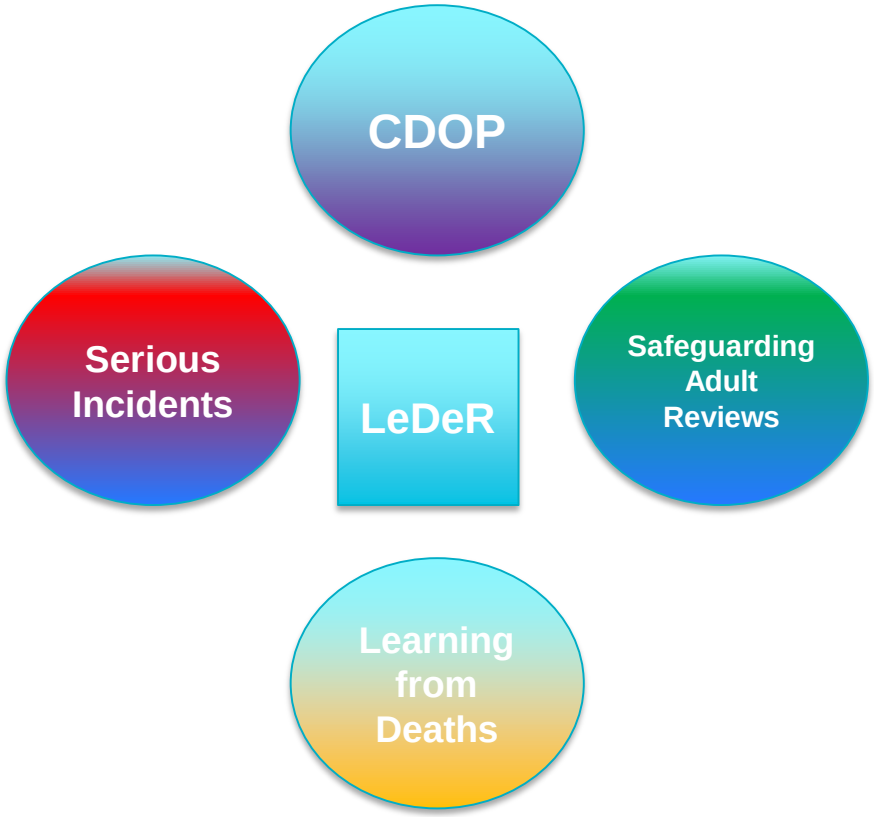
Challenges encountered

- Initial information in the LeDeR notification may not indicate safeguarding
- Safeguarding not always recognised at the early stage of an initial LeDeR review
- Duplicate work when referred for safeguarding adult review

LeDeR methodology



Other investigation processes



- **CDOP** reports are uploaded to LeDeR system
- Hospital based '**Learning from Deaths**' review reports should be provided to LeDeR reviewers
- **SI** & **SAR** reviewers should negotiate roles/responsibilities with LeDeR reviewers
- Unnecessary replication should be avoided to maximise opportunities for learning

Death notified to LeDeR

- LeDeR Initial Review carried out
- Findings: “care fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person
- Case eligible for a LeDeR Multi Agency Review

Referral to safeguarding adults

- A local safeguarding adult’s multi-agency meeting was held.
- The meeting concluded that the person experienced neglect by omission and identified missed opportunities for agencies to have worked better together to support the person which may have contributed to their death.

Safeguarding Adults Review commissioned

- Practitioner event.
- Combination of the Significant Event Analysis methodology and LeDeR Multi-Agency Review (MAR) format
- Independent chair

Outcomes

- SAR report
- Information from SAR report feeds directly into MAR
- Action plan for services draw up at meeting

Limitations

- The information considered as part of the SAR was gathered as part of the LeDeR process
- Agencies were asked to come prepared for the meeting with information in relation to the key themes identified by LeDeR
- This possibly narrowed the lens through which the care was explored.

Next Steps: Pilot process looking at a 2nd case joining up the LeDeR process with SAR's.

Evaluation and positive feedback

06/02/2019

- An Independent Chair was commissioned to ensure transparency
- Engagement from stakeholders - group led
- Yields learning for improvements quickly - Action plan drawn up in a timely way
- Enables practitioners to explore root cause of decision making in practice.
- Attendee feedback - “particularly where chronologies have already been completed. Some SARS take so long that staff / teams have left or disbanded etc. before the learning can be shared or discussed.”

Discussion Questions

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