Learning Disabilities Mortality Review (LeDeR) Programme

NHS England

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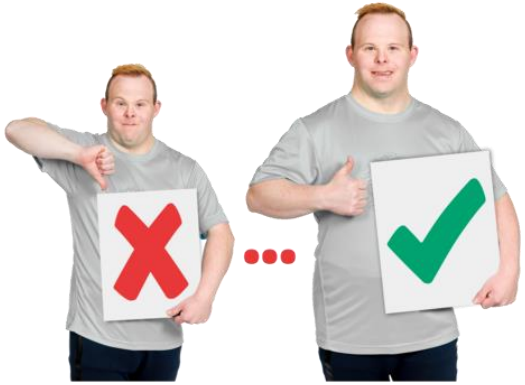
The Learning Disability Mortality Review LeDeR Programme



- All deaths of people with Learning Disabilities aged 4+ will be reviewed
- The process identifies “potentially avoidable contributory factors” across health & social care
- Aims to reduce health inequalities & premature mortality through:
  - Sharing best practice
  - Identifying areas for improvement
  - Establishing local multi-agency steering groups overseeing implementation of ‘action plans’ from completed reviews

Programme Progress Update

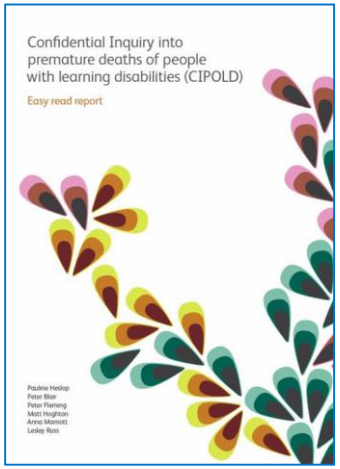
Challenges

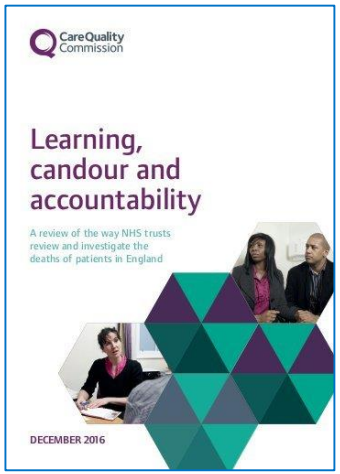
- Delays in review allocation & completion
- Access to information
- Some reviews have overlooked potentially avoidable factors

Next Steps

- A further £1.4 million for LeDeR
- GP/clinical champions for LeDeR
- Focus on Quality Assurance

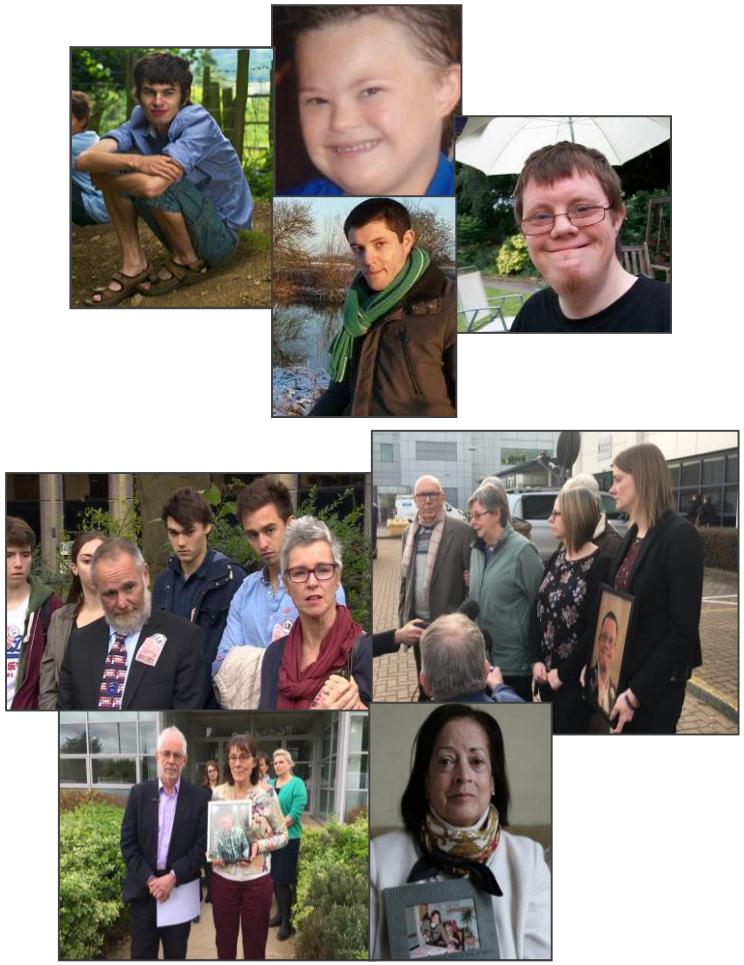
Why is LeDeR so important?





- **Death by Indifference (2007)**: People with LD dying due to “institutional discrimination” in the NHS
- **Confidential Enquiry into Premature Deaths of People with Learning Disabilities (CIPOLD, 2013)**: People with LD dying 13-20 years younger than general population
- **Learning, Candour & Accountability (CQC, 2016):** Learning from deaths has not been prioritised, with particular issues highlighted for people with D

Involving Families in LeDeR



CQC, 2016:

- Bereaved families have not experienced services as open & transparent.

- Opportunities have been missed to learn from preventable deaths & improve services.

LeDeR:

- LeDeR reviewers are required to involve families to
  - harness their knowledge
  - reassure families
  - fulfil the duty of candour

LeDeR's Annual Report - findings to date

- 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

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

LeDeR's Annual Report - findings to date

- 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%

End of Life Care

Good Practice

- Proactive planning, across agencies
- Pain
- Involving families
- “Bucket lists”
- Person at the centre
- Dying in a place of their choosing

Areas for improvement

- “Training”
- Planning too late
- Anxiety amongst care home staff
- Unexpected deaths without advanced planning
- Communication with families

“Death” Inequalities

- Place of Death:
  - Hospital: 64% (47% in gen. pop.)
  - Home: 30%
  - Hospice / palliative care unit: 2%
- Additional Investigations:
  - Post Mortems: 12%
  - Coroners Inquests: 5%
  - Other review process: 12%

- LeDeR reviewers are identifying safeguarding & serious incidents that were not yet reported.

Learning & Recommendations

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
4) End of life care / planning
5) DNACPR

Local service change is required to address these familiar “lessons”

“Learning” into Action

Local Steering Groups:

- Map local “issues” via completed reviews
- Ensure ‘action plans’ are implemented & monitored
- Provide evidence to NHSE of multi-agency service improvements

National Learning into Action Network:

- Resource repository
- Online engagement with learning & best practice
- Email emily.handley1@nhs.net to join

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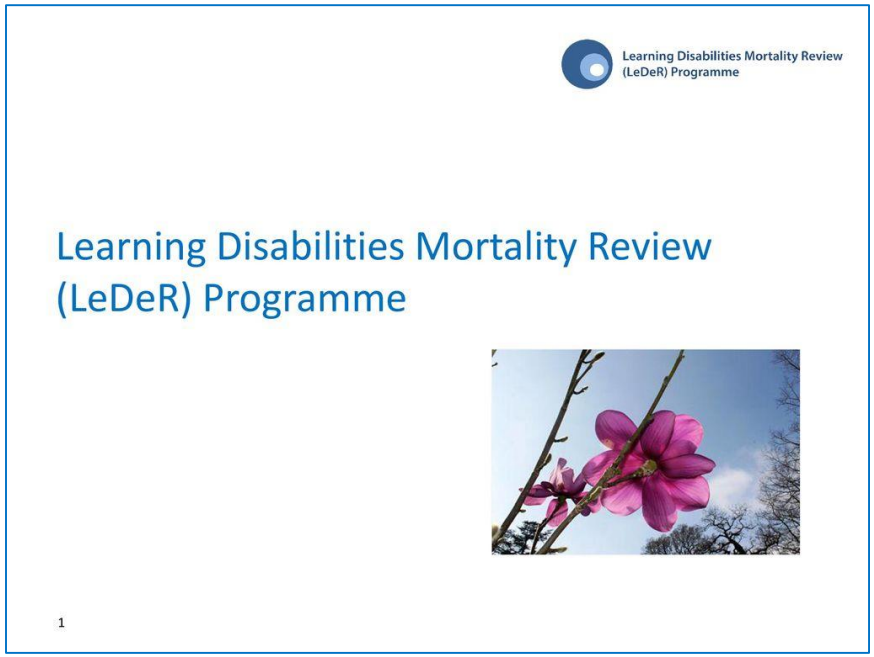
Supporting the LeDeR programme

"In our story, we stepped up and each did what we could in myriad ways with integrity, tenacity, humour and a dose of bold"
Sara Ryan (Conner's Mum)



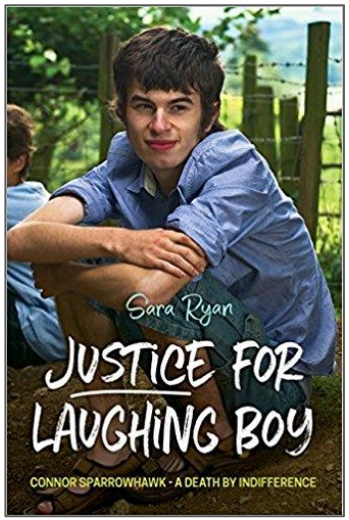
1) Notifying deaths of people with Learning Disabilities
   http://www.bristol.ac.uk/sps/leder/notify-a-death/

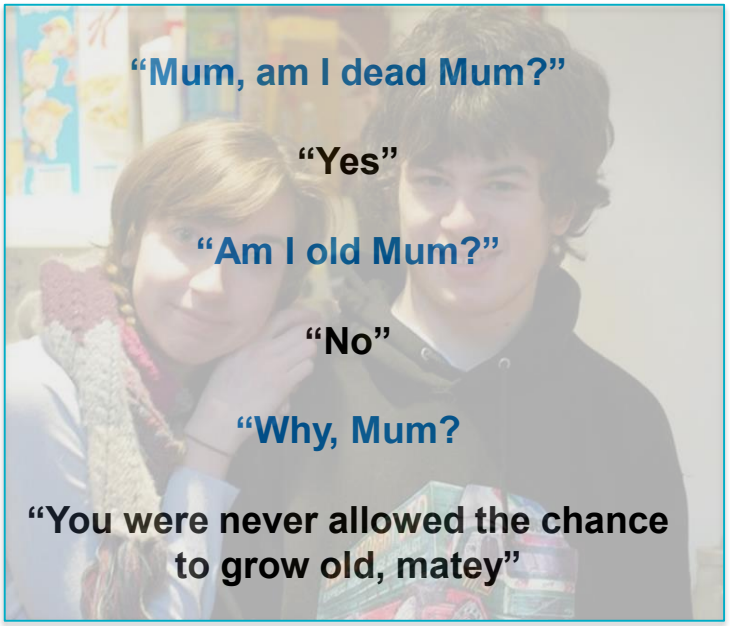
1) Train as a LeDeR reviewer
   Book via emily.handley1@nhs.net

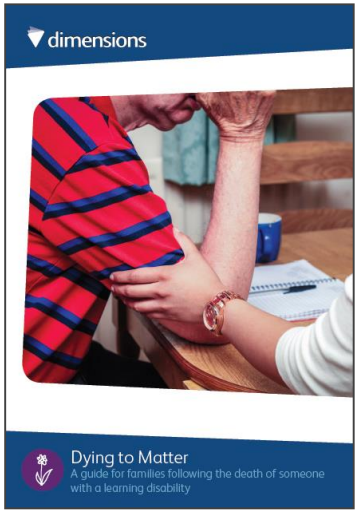
2) Seek info. re local learning / service improvements via LeDeR steering groups

3) Join national learning-into-action network

Recommended Reading







DyingToMatter: A guide for families following the death of someone with a Learning Disability (Dimensions, 2018)

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