1) Introducing the LeDeR Programme
2) The LeDeR Annual Report
3) Reflection & Discussion

The Learning Disability Mortality Review LeDeR Programme

- All deaths of people with Learning Disabilities aged 4+ will be reviewed
- 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

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
- Mazars Report into Southern Health (2015): <1% LD deaths reviewed
- Learning, Candour & Accountability (CQC, 2016): Learning from deaths has not been prioritised, with particular issues highlighted for people with LD

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

The National Mandate

- The Learning From Deaths guidance states that all deaths of people with learning disabilities in acute, specialist and community trusts need to be reviewed using LeDeR methodology.
- CQC inspection requires evidence of learning from MH/LD mortality reviews
The LeDeR methodology

- Initial Review: A LeDeR steering group is established in every London borough.
- Each NHS provider trust, LA & CCG in London has an organisational lead for LeDeR.
- Service improvements are monitored via:
  - Borough steering groups
  - Pan-London steering group
  - National operational steering group

Potentially Modifiable 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.

LeDeR Steering Groups

- A LeDeR steering group has been established in every London borough.
- Each NHS provider trust, LA & CCG in London has an organisational lead for LeDeR.
- Service improvements are monitored via:
  - Borough steering groups
  - Pan-London steering group
  - National operational steering group

Learning & Recommendations

Issues
- What were the potentially modifiable factors?

Learning
- What can we learn from them?

Recommendations
- How can we make sure this doesn’t happen again?

Best Practice

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
- Closer performance management
- Focus on Quality Assurance

2) The LeDeR Annual Report
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.

There are approximately 1,200 deaths in England every year of people with LD that could have been avoided through good quality healthcare.

This is an equivalent to a mid-Staffordshire scandal every year for people with LD.

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

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”
3) Reflection & Discussion

Factors which may impede progress in reducing inequalities / premature mortality

- Societal discrimination?
- Do LD specialists unwittingly overwhelm mainstream staff when criticising & championing?
- Does the focus on targets dehumanise staff/patients & impede flexible patient care?
- Do medics unconsciously seek to protect pwLD from pain/distress?
- Do NHS staff wear a handicapped smile & unconsciously collude with bureaucratic constraints, in order to survive?


Reflection: Potentially modifiable factors?

- High/low BMI (capacity?)
- Medication side effects/ STOMP
- Need for health advocacy from LD professionals
- Hospital passports & annual health checks
- Are services reactive or proactive?
- Supporting Desensitisation
- Dichotomy between physical & mental health (?holistic)
- Diffusion of responsibility
- Physical health is everyone’s business!!

Discussion

What changes are we all going to make to our practice to make sure we are part of the solution?

“In our story, we stepped up and each did what we could in myriad ways with integrity, tenacity, humour and a dose of bile.”

Sara Ryan (Connor Sparrowhawk’s Mum)

Your role in the LeDeR programme

- Complete notifications of deaths
- Become a LeDeR reviewer
- Support development of a culture wherein mortality review is routine
- Implement learning from completed reviews (via steering group)
- Workforce development: trainees
- Research & audit
- See ‘recommended reading’
“Mum, am I dead Mum?”

“Yes

“Am I old Mum?”

“No

“Why, Mum?”

“You were never allowed the chance to grow old, matey”

Recommended Reading

Learning lessons from the aviation industry.

“Creative breakthroughs always begin with multiple failures. This brilliant book shows how true invention lies in the understanding and overcoming of these failures, which we must learn to embrace.”

James Dyson (Inventor)

Contact Details

LeDeR Bristol:
lder-team@bristol.ac.uk
Tel: 0117 3310686
Website: www.bristol.ac.uk/sps/leder

NHS England LeDeR London Region
Regional Co-ordinator:
emily.handley1@nhs.net
GP Champion: nicolapayne@nhs.net