What is LEDER?

• Nationally commissioned programme
  • Review the deaths of people with LD
  • Learning points and themes
  • Take action

• How might you be involved?
  • It’s part of your contract!
  • Notifying the death of a person
  • Input into a review
What are the issues?

Access to healthcare
A number of barriers are stopping people with a learning disability from getting good quality healthcare. These barriers include:

- a lack of accessible transport links
- patients not being identified as having a learning disability
- staff having little understanding about learning disability
- failure to recognise that a person with a learning disability is unwell
- failure to make a correct diagnosis
- anxiety or a lack of confidence for people with a learning disability
- lack of joint working from different care providers
- not enough involvement allowed from carers
- inadequate aftercare or follow-up care
What are the outcomes?

- Women with LD live 18 years less than other women (av age 59)
- Men with learning disabilities live 14 years less than other men (age 60)
- 62% of people with LD say they feel anxious or depressed
- 63% of people with learning disabilities die in a hospital bed
- A government enquiry found 38% of people with LD died of an avoidable cause

"Of particular concern...misreading symptoms of illness as being due to a person having a learning disability rather than a treatable medical condition." (LeDeR Report)
Where we are

• A large number of people in residential care
• Some evidence of lack of communication between care providers and the NHS
• Around 45 LEDER reviews completed
• A backlog of 100+ reviews
• A number of recurring themes

AND!
• Some fantastic examples of sharing learning
• Purple All Stars / Health Liaison Team / LD Nursing
• Purple folder and deep understanding of issues
• A commitment from our leaders to do better
Firm Foundations

1. Joint commissioning in Hertfordshire
   - We have commissioned and jointly delivered learning disability services for many years, with no plans to stop
   - Our ‘Connected Lives’ approach will ask our providers to think more broadly about what people want and join up
   - We are thinking about a specific partnership to deliver services for people with specialist needs – so we don’t go backwards in terms of parity of services for people
The Role of the STP

2. Sustainability and Transformation Partnerships

• Encouraging NHS, social care and other partners to work more closely together for cohorts of people
• Acknowledge that people don’t want to be ‘patients’, want to be independent and only want a reasonable adjustment
• Get a better deal from the health service on the physical and emotional health of people with learning disabilities
• Have a ‘population health management’ approach to reduce health inequalities – like this one.
4. Productive partnerships

- Housing & leisure (including investment to support needs of rough sleepers; Healthy New Towns standard)
- district councils (key partners)
- police & crime commissioners
How you can help us

Help us to keep momentum

• We need to have more system and less silo working
• Get the message out in your organisations – this is a real inequality and we should be outraged!
• Keep sharing positive practice
• Maximum effect when we work together
• Support staff involved in this work
• Co-production with people and their families
Thank you for your time and support