SYSTEM 4 Data & Evidence

Learning Disabilities Mortality Review (LeDeR) in the UK

MISSING BILLION

Geography and scale:	England, national.
Type of disability:	Children and adults with learning disabilities

Involved actors

- Department of Health
- National Health Service (NHS) England
- Health Quality Improvement Partnership
- University of Bristol

Best practice description

Established in 2015, the LeDeR programme is a novel program to help reduce premature mortality and health inequalities among people with learning disabilities, as well as to improve the quality of health and social care delivery. Its key components are:

- Every person with learning disabilities who dies has a local review of their case notes and cause of mortality to write a report. The report reviews potentially modifiable factors of their death, such as the level of care received, involving other agencies to contribute to the investigation whenever necessary.
- All local reviews are submitted to the programme and analysed at a national level. Reports include main causes of death and good practices, which are compiled into an annual report with recommendations. This report is also translated into an easy-to-read format.

Origin / impetus for best practice

- Mencap's report, Death by indifference, 2007, described cases of institutional discrimination and avoidable deaths of persons with learning disabilities, and called for an urgent independent inquiry.[1]
- The Michael report (2008) revealed that people with learning disabilities had higher levels of unmet needs, received less effective care and had higher risks of avoidable deaths than the general population.[2]
- Findings of the Confidential Inquiry (2013) showed that avoidable deaths of people with learning disabilities were related to quality of care and service provision. Recommendations included the review of deaths, routine collection of mortality data, and the establishment of a national review board.[3,4]
- See related good practice description in our compendium: Learning Disability Registries.

Impact / results of implementing best practice

The findings from the annual reports have led already to significant changes in practice:

- NHS England set out a long term plan to implement national learning disability improvement standards.
- Health and care staff will receive learning disability and autism training.
- Health system changes in local areas are analysed and shared in action from learning reports.

Critical success factors for best practice

- Mencap's initial data on early deaths.
- Strong advocacy from the learning disability community.
- Political will for collaboration.
- Dedicated funding from NHS England.

Impact statement

"The disparity between people with learning disabilities and the general population in relation to average age at death, causes of death, and avoidable causes of death remains substantial and urgent action is needed"

Professor Pauline Heslop; LeDeR Programme Lead. 16th July 2020 on this link.

Lessons learned

- Reviews have to be high quality and completed in a timely fashion.
- Reviews are not mandatory and reporting rates vary by area; commitment to implementation should be strengthened.
- Mortality trends (cause, geographic location,etc.) can be used to inform policy and research.

Sources

[1] Mencap's report 2007
[2] Healthcare for all, Michael Report 2008
[3] Confidential Inquiry 2013
[4] Heslop P, Blair PS, Fleming P, et al. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. Lancet (London, England) [Internet]. 2014 Mar 8;383(9920):889–95. Available from: http://www.ncbi.nlm.nih.gov/pubmed/24332307

Further links & information

- LeDeR programme - University of Bristol
- Action from learning – NHS
- Learning disability improvement standards

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