Learning Disabilities Mortality Review (LeDeR) Programme

Information pack for Rutland County Council Adults and Health Scrutiny Panel

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Learning Disabilities Mortality Review (LeDeR) Programme

Introduction

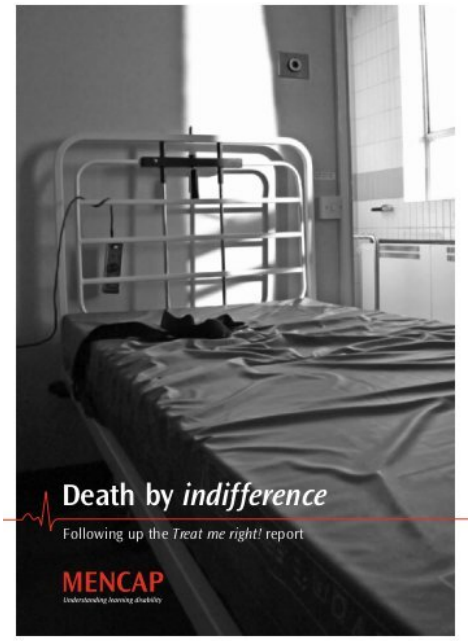
From the LeDeR Annual Report (2017)

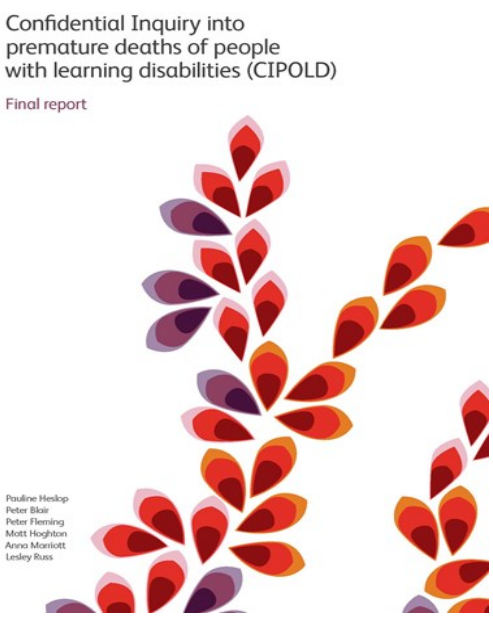
The persistence of health inequalities between different population groups has been well documented, including the inequalities faced by people with learning disabilities (LD). Today, people with learning disabilities die, on average, 15-20 years sooner than people in the general population, with some of those deaths identified as being potentially amenable to good quality healthcare.

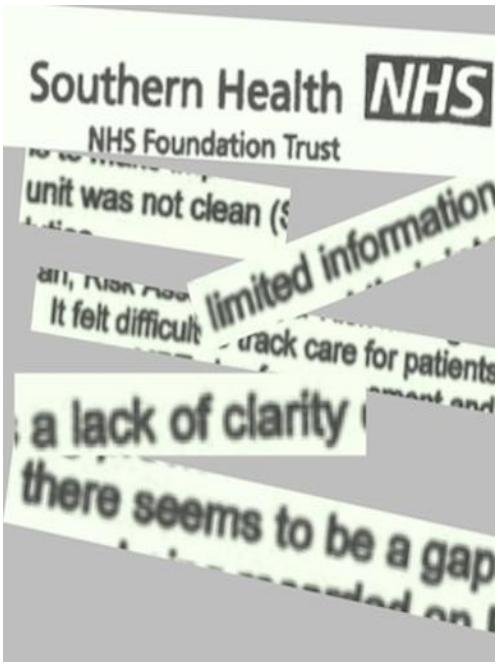
The Learning Disabilities Mortality Review (LeDeR) programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives. It is being implemented at the time of considerable spotlight on the deaths of patients in the NHS, and the introduction of the national Learning from Deaths framework in England in 2017. The programme is led by the University of Bristol, and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

From Mencap to Southern Health – LeDeR's origins

For over 10 years there have been a series of investigations, reports and scrutiny placed on health and social care services delivered for people with learning disabilities. LeDeR aims to address the inequalities, inconsistencies, and what has been determined 'institutional discrimination' that these reviews and reflections have brought to national attention.







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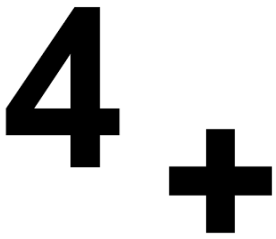
The LeDeR Process



Anybody over the age of 4 years old with a diagnosed learning disability is required to have a review of their health and social care services after their death

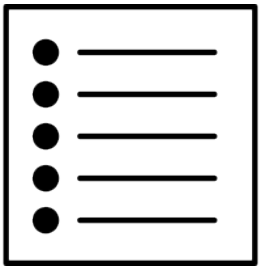
A referral to the LeDeR programme is made either online or over the phone. Details can be found at http://www.bristol.ac.uk/sps/leder/

Referrals are then sent to the LLR local area contact for allocation to an available LeDeR reviewer.

For LLR LeDeR reviewers are usually Nurses from the two NHS Trusts or Social Workers from the three local authorities. They are specially trained in conducting LeDeR reviews.

The allocated LeDeR reviewer will discuss the person – their life, aspirations, what they enjoyed doing – with their family, friends, carers and involved professionals.

They will also review case records from all major organisations involved. This includes hospital records and local authority assessments and support plants.



They will use this evidence as the basis for their LeDeR review. This includes a pen portrait of the person and a timeline of their care leading up to death.

The review ends with a score of the person's care and an outline of any identified learning. If there were significant concerns a further multi-disciplinary review could be convened.

Once approved the reviews and recommendations are then passed to the LLR LeDeR Steering Group for discussion. This could lead to the development and implementation of Action Plans to improve services.

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Leicester, Leicestershire and Rutland (LLR) LeDeR

Approximately 15,500	Estimated number of people with a learning disability across LLR*
October 1st 2017	LeDeR programme goes live across LLR
50	Indicative projection for LD deaths across LLR each year
49	Actual number of deaths reported to LLR LeDeR during the first year (October 1st 2017 – September 30th 2018)
84	Total LLR LeDeR referrals to date
28	Trained / in training LeDeR reviewers
38 (45%)	Referrals allocated / in process of allocation to a LeDeR reviewer
36 (32%)	Referrals awaiting allocation
2 (3%)	Reviews going through Quality Assurance process
8 (10%)	Completed reviews

*Pansi data as cited by East Leicestershire and Rutland CCG 'LLR Transforming Care Plan' https://eastleicestershireandrutlandccg.nhs.uk/wp-content/uploads/2013/01/LLR-Transforming-Care-Plan-April-2016-2.pdf

Data Protection & Information Sharing

The LeDeR programme has undergone extensive work to ensure the people's data is protected in line with stipulations of contemporary legislation (including GDPR). In recognition of this work the LeDeR programme has obtained on a national level Section 251 approval from the Secretary of State to handle personal data without consent to conduct mortality reviews; on a local level an information sharing agreement signed by health and social care partners to this end. For more information visit http://www.bristol.ac.uk/sps/leder/ or contact James Lewis.

Information Sharing Agreement

Between

Learning Disabilities Mortality Review (LeDeR) Programme

and

Partners from Health and Social Care organisations within

Leicester, Leicestershire and Rutland Region

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Some initial findings…	LeDeR Annual Report (01.01.17 – 31.12.17)		Leicester, Leicestershire & Rutland to 11/18	
Age at death	Mild	63	Mild	64
	Moderate	63	Moderate	64
	Pro/Sev*	41	Pro/Sev*	49
	All LD	58	All LD	56
Deaths under age of 50	28%		22%	
Most common cause		41% of deaths reported as pneumonia		40% of deaths reported as pneumonia
Place of death	Hospital	60%	Hospital	58%
	Residence	34%	Residence	38%
	Other	5%	Other	4%
Usual residence	Residential	n/a	Residential	44%
	Supported Living	n/a	Supported Living	38%
	Independent	n/a	Independent	18%
Lived alone	9%		10%	
Ethnicity		93%		90%
		7%		10%

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*Profound and severe learning disabilities

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Map of LeDeR referrals to date by the person's address (23.01.19)

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Leicester, Leicestershire & Rutland LeDeR's priorities

- Recruit further LeDeR reviewers
- Continue to raise awareness of the programme with stakeholders. Presentations have been delivered to health and social care professionals, the voluntary and community sector and service user participation groups; LeDeR correspondence sent to health and social care providers across Leicester, Leicestershire and Rutland.
- Begin to formulate Action Plans based upon the findings of completed LeDeR reviews
- Integrate LeDeR into LLR's programme of work to improve services for people with learning disabilities

How you can contribute to the LeDeR programme

- Refer the deaths of anyone over the age of 4 with a diagnosed Learning Disability to the programme (http://www.bristol.ac.uk/sps/leder/notify-a-death/ or 0300 777 4774)
- Provide information to a LeDeR reviewer if asked for it. All key health and social care organisations have signed up to the local information sharing agreement for the purposes of the programme.
- Become a LeDeR reviewer. We are in particular looking for those whom have experience in working with people with learning disabilities in a health or social care setting. For more information please contact James Lewis.

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