

01 Background:

The Learning Disabilities Mortality Review (LeDeR) Programme was established as a result of one of the key recommendations of the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). CIPOLD reported that some people with learning disabilities were dying sooner than they should. Some of the reasons for this were related to the standard of health and social care that they received. The LeDeR Programme is run by the University of Bristol from 2015-2018. It is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. The LeDeR Programme aims to make improvements to the quality of health and social care for people with learning disabilities.

02 What LeDeR does:

A major part of the LeDeR Programme is to support local areas in England to review the deaths of people with learning disabilities aged 4 years and over. Local reviewers will be looking at all deaths, regardless of the cause of death or place of death. LeDeR hopes to help health and social care professionals and policy makers to identify what works well to support people with learning disabilities to live long and healthy lives; Identify factors which may have contributed to deaths of people with learning disabilities and develop plans of action to make any necessary changes to health and social care services for people with learning disabilities.

07 More information

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Families:

Anyone can refer an individual into the programme, provided there is a learning disability diagnosis. A confidential telephone number and website enables this. Families, friends and other key people can also contribute their views by speaking with the person conducting the review in their locality. They can do this either by telephone or face-to-face.

Learning Disabilities Mortality Review (LeDeR) Programme

03 Information:

For each death there is an initial review. The purpose of this is to collect information that establishes if there are any concerns relating to the care of the person who has died or if any further learning could be gained from a more in-depth review of the death that would contribute to improving the health and social care provided to people with learning disabilities.

Process:

The person's death is notified to the national team in Bristol. The person must have a learning disability diagnosis. Bristol then refer to the Local Area Contact (LAC) in Heywood, Middleton and Rochdale CCG.

The LAC identifies a reviewer who is on a register. The reviewer submits their report after medical and social care records have been evaluated and the family and friends have been invited to contribute their views.

Information:

If there are any areas of concern identified about the death, or if it is felt that a fuller review could lead to improved practice, a more in-depth or multi-agency review takes place.

- The review looks at three levels of care:
- a) Initial diagnosis and management of the condition.
 - b) Ongoing management of the condition from initial diagnosis to critical illness.
 - c) Management and care received during final illness.

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