| Report to: Plymouth Safeguarding Adults Board | |
|---|---|
| Date of meeting: | 5th October 2017 |
| Author: | Lorraine Webber,<br>Deputy Director of Quality Assurance & Improvement (SDT CCG)<br>Simon Polak, Deputy Chief Nurse (NEWD CCG) |
| Title of Report: | **Learning Disabilities Mortality Review (LeDeR) Programme for Devon** |

**Background**

Since the 1990s there have been a number of reports and case studies that have consistently highlighted that in England people with learning disabilities die younger than people without learning disabilities. The Confidential Inquiry into the premature deaths of people with learning disability (CIPOLD) reported that for every one person in the general population who died from a cause of death amenable to good quality care, three people with learning disabilities would do so (1).

More recently, analysis of data from the Primary Care Research Database (2) suggested that people with learning disabilities had a life expectancy 19.7 years lower than people without learning disabilities.

The Learning Disabilities Mortality Review (LeDeR) Programme has been commissioned by NHS England and established in response to the recommendations made by CIPOLD and has been set up to contribute to improvements in the quality of health and social care for people with learning disabilities in England. It is also recommended by the National Quality Board in their 'Learning from Deaths Programme' published April 2017.

**The LeDeR Programme**

The LeDeR programme provides guidance for the conduct of reviews of the deaths of people with learning disabilities and will support local areas to carry out local reviews. Through an agreed local review process, it aims to firmly embed the responsibility for conducting the reviews and implementing any recommendations and plans of action, into the hands of regional and local services.

The main purpose of the LeDeR review of a death of a person with learning disabilities is to:

- Identify any potentially avoidable factors that may have contributed to the persons death and
- Develop plans of action that individually or in combination, will guide necessary changes in health and social care services

Inclusion criteria for reviews under the LeDeR programme are:

- Initial reviews are undertaken of **all** deaths notified to the LeDeR programme of people with learning disabilities aged 4 and above who are registered with a GP in England.
- Deaths in adults with a learning disability aged 75 or over are not subject to a LeDeR review.

**Establishing the LeDeR Review Process**

The SDT CCG Director of Quality initially agreed to act within the Executive Lead role in the Devon STP area.

An implementation group is in place and an implementation plan in progress (Appendix 1)

A **Local Steering Group (LSG)** will be established for Devon (STP footprint) and will have responsibility for:

- Guiding the implementation of the programme of local reviews of deaths of people with learning disabilities
- Receiving regular updates from the local area contact about the local reviews of deaths of people with learning disabilities
- Monitoring action plans resulting from local reviews of deaths
- Taking appropriate action as a result of information obtained from local reviews of deaths
- Resolve any interagency disputes that arise

Anticipated date of first steering group will be Sept/October 2017.

**Local Area Contact**

Local area contacts are the link between the central LeDeR programme team, the Local Steering Group and local reviewers. There will be 2 local area contacts for Devon and their role will be to work in partnership with the LeDeR team in organising the delivery of training for local reviewers, and more general awareness raising about the programme

In addition they will receive notifications of deaths of people with learning disabilities from the central LeDeR programme team and help allocate cases to appropriate local reviewers. They will monitor the progress and completion of reviews to ensure that they are of a consistent standard and completed in a timely and comprehensive way and provide ongoing advice, support and training for local reviewers as necessary.

Local area contacts will also liaise with the Local Steering Group about any issues that arise in relation to the reviews of deaths, receive and sign off completed review documents and action plans, anonymise and collate learning points and actions, and present the information to the Local Steering Group for action and implementation.

The area in which the person is registered with a GP will lead the review.
If a person is in an 'out of area' placement the area in which the person is registered will lead the review unless there are compelling reasons why this should not be the case. In such

circumstances, discussion is required between the sending and receiving areas to agree which would lead the review and how best to collaborate.

- South Devon & Torbay (CCG area) LAC – Lorraine Webber, Deputy Director of Quality Assurance & Improvement (Lead Nurse), Tel: 07769 324515 or email lwebber@nhs.net
- NEW Devon (CCG area) LAC – Simon Polak, Deputy Chief Nurse, Tel: 07896 198812 or email simon.polak@nhs.net

**Local Reviewers**

The reviews should be undertaken using the secure web-based LeDeR review system, with all review documents completed on-line and any additional case notes and supporting paperwork stored within the LeDeR review system.

It is anticipated that around 32 local reviewers will be required across Devon and this has been estimated based on historical data of deaths over 1 year:

| Area | Deaths in 1 year | Estimated no. of reviewers |
|---|---|---|
| Bristol | 55 | 22 |
| Somerset | 34 | 14 |
| Cornwall | 39 | 15 |
| Devon (incl Torbay) | 80 | 32 |

There has not been data made available to identify the age of previous deaths however reviewers will need to be a mix of individuals from across both adult & childrens services. They will be responsible for undertaking robust and high quality reviews of the deaths of people with learning disabilities following the LeDeR methodology. Reviewers will receive training and support from the LeDeR team and locally from the LAC.

At the end of July training has been undertaken across Devon for both local area contacts and 15-20 reviewers from across CCG's and provider organisations. A further 4 reviewers are booked for training in September.

Local reviewers will undertake the 'initial review' and this process will determine if a multi-agency review is required. A **multi-agency review** should be considered if the local reviewer thinks that a multi-agency review would be appropriate, even though their initial assessment does not include any 'red flag' responses or when any red flag alerts are indicated in the initial review. Additionally a multi-agency review should be considered if there have been any concerns raised about the care of the person who has died.

**Data Sharing & Confidentiality**

Due to the complex and multi-agency nature of the reviews it is important that information sharing is in line with expectations regarding confidentiality and the appropriate use of received information.

The LeDeR programme has Section 251 approval (CAG reference: 16/CAG/0056) for the use of patient identifiable information in order for reviews to be undertaken of the deaths of people with learning disabilities.

Where the LeDeR review overlaps/links with other mortality reviews, to avoid duplication reviewers need to be clear how, and in what ways, the LeDeR mortality review process links with other mortality reviews or investigations. The Local Area Contact is responsible for informing the LSG about each LeDeR review that significantly impacts on or is affected by another investigation or review, sharing the agreed plan for data collection and providing the Local Steering Group with reports on progress and completion of the review.

**Involving families in the review process**

Families should be encouraged and supported to be involved throughout the entire review process or as much as the family feel able or want to be involved. Information & resources are also available to support the family.

**Types of review**

- **Initial –** undertaken by the local reviewer within 4 weeks
- **Multi-agency –** undertaken where 'red flags' or concerns are indicated on initial review and completed within 90 days from initial review
- **Priority themed –** deaths of people with learning disabilities who fit the criteria for priority themed review are subject to a full multi-agency review, and the anonymised reports and action plans reviewed externally by an independent, multi-agency review panel. Two panels are in existence: one is a multi-agency panel of professionals and family members. The second panel is of people with learning disabilities.

**Quality Assurance**

The local area contact is responsible for quality-assuring each initial and multi-agency review that is undertaken in their local area.

The Steering Group will be responsible for producing regular quality assurance reports and ensuring recommendations and action plans that support practice, process or system change are produced and monitored.

The Regional & National LeDeR team will also undertake reviews and themed analysis that could support the local Steering Group.

**Governance**

The outputs from the LeDeR programme need governance and oversight at local, regional and national level, to ensure any appropriate management action is taken as required, and that themes and lessons are fed into service improvements.

**Local level governance** - All areas should have a local steering group established. The preferred geography would be utilising existing Transforming Care Partnership footprints or other learning disability-focussed commissioning networks. The local steering group provides oversight, support and governance to the local delivery of the programme, and oversees how the programme is administered and delivered in the local area.

The local steering group should provide updates and assurance to:

- The central LeDeR team at the University of Bristol
- The named lead for the programme in their respective NHS England region (North, South, Midlands, London)
- The national Operational Steering Group.

**Impact/Risks**

Reviewers have been identified from across the CCG footprint and include many individuals/roles that are already actively involved in case reviews and therefore have key skills. Training & support time for reviewers has initially been required.

No additional resource or funding has been provided to CCG's to support the implementation of this programme and the additional time for Local Area Contact and reviewer work will need to be picked up within current roles.

There may also be a requirement to source administrative support for co-ordinating the steering group.

Potential links & overlaps with other statutory review/investigation functions eg CDOP/Safeguarding. The National Leder team have developed guidance to support this and locally we have completed more detailed analysis to identify the overlaps and to guide both LAC and reviewers (Appendix 2)

**Key Milestones**

The implementation plan (Appendix 1) details all areas completed and outstanding.
A 'go live' start date for Devon has been agreed for 1st October 2017.
NHS England are commencing a South West regional Steering group in August 2017.
NHS England are providing briefings to Chairs of local SAB's/LSCB's and CDOP.

**References**


(1) Heslop P, Blair P, Fleming P, Hoghton M, Marriott A, Russ L. (2013) *The Confidential Inquiry into premature deaths of people with learning disabilities. Final Report*. University of Bristol. Bristol. http://www.bristol.ac.uk/media---library/sites/cipold/migrated/documents/fullfinalreport.pdf

(2) Glover G, Williams R, Heslop P, Oyinola J, Grey J. (2016) Mortality in people with intellectual disabilities in England. Journal of Intellectual Disabilities Research. Early view. Doi: 10.1111/jidr.12314