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# NEWSLETTER

**November 2017**

**Improving the lives of people with learning disabilities**

Welcome to the FIFTH edition of the Learning Disabilities Mortality Review Programme newsletter. We hope you enjoy reading about the LeDeR Programme. Thank you for your support!

## Roll-out progress

The LeDeR programme's first phase of roll-out is to ensure that by the end of 2017 LeDeR steering groups are set up across England, that they have staff trained in the LeDeR methodology, they are being notified of deaths of people with learning disabilities, and the deaths are being reviewed. All four NHS regions are on track to meet this target.

By October 2017, the programme has trained over 180 Local Area Contacts and over 1,300 reviewers. There have been over 1,400 notifications of deaths, and of these, over 1,100 are within the scope of the programme.

### NHS England North

Progress continues in relation to engaging families and people with learning disabilities. Communication plans have been revisited to ensure localities increase the awareness of LeDeR. Work priorities are to ensure that reviewers can meet demand and are actively supported to undertake reviews at a local level.

### NHS England Midlands and the East

Local areas are finding innovative approaches to implementation, working closely with local partners including self-advocacy groups, carers organisations and advice and information services. All areas across the region have been reviewing deaths since 1st October 2017.

### NHS England South

There has been greater alignment across the South East, South West and South Central in terms of progress. Local Area Contacts have been trained and are engaged in all 51 CCGs. South East and South Central have been receiving notifications of deaths from August and September 2017.

### NHS England London

All deaths of people with learning disabilities are being reviewed. Current priority is to deliver Local Area Contact training to CCG leads. A lead for each of London's five Sustainability and Transformation Partnership (STPs) has been identified and induction meetings have taken place.

## LeDeR 2017 Interim Annual Report

The LeDeR interim annual report using infographics is available on the LeDeR website:

<http://www.bristol.ac.uk/sps/leder/news/2017/read-leder-interim-annual-report-infographic.html>

## In the previous issue:

- Roll-out progress in four regions
- Involvement of families
- Focus on: The pan-London LeDeR roll-out
- Update on LeDeR training
- Learning from Deaths programme
- Priority Themed Reviews
- Regional workshops
- Evaluation of LeDeR pilot sites



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## Focus on

### Derbyshire (Midlands and the East)

From 1st April 2017 Derbyshire has been receiving notifications of deaths of people with learning disabilities; 18 deaths have been reported. There are currently 23 trained reviewers in Derbyshire but most reviews have a Lead Reviewer and a Buddy Reviewer, so all reviewers are presently working on a review. Of the 18 reviews, 3 have already been completed; one of which went to a Multi-Agency review.

Derbyshire has received feedback from the Bristol team and NHSE regarding the good standard of the completed reviews, and all credit goes to the Derbyshire reviewers who have invested time and effort into delivering full and detailed reviews. Of the remaining 15 reviews, one review is a Priority Themed review and will therefore automatically receive a Multi-Agency review. The Derbyshire Steering Group has a varied list of members with carers and an expert by experience attending meetings; it is chaired by a lay member. The group is currently working with NHSE and the Bristol team to produce an action plan of how the recommendations from the reviews of deaths can be actioned across Derbyshire.

If anyone is interested in becoming a Derbyshire reviewer or requires any further information, please contact

[lisa.coppinger@nhs.net](mailto:lisa.coppinger@nhs.net)

## Film for families

We would like to meet family carers who have taken part in a LeDeR review and would be willing to talk about this for a short film we are making for families. If you can help put us in touch, please contact

[leder-team@bristol.ac.uk](mailto:leder-team@bristol.ac.uk)



# Learning Disabilities Mortality Review (LeDeR) Programme



## Welcome to new staff!

In the last few months the LeDeR team has been joined by Anni Sutt (Office Administrator) who provides administrative support for the Programme.

## Meet Dave:

### our Information Officer/ easy-read

My name is Dave. I have been a member of the Learning Disabilities Death Review (LeDeR) programme team for five months. It has been amazing. This is my story so far.

I think the LeDeR Programme is important because it's about reviewing deaths of people with learning disabilities. So it's a good idea to have someone with learning disabilities working with the LeDeR Programme. Eventually this will help people with learning disabilities get the right care and treatment. A key role of mine is to create easy read material for other people with learning disabilities. Working at the university has been interesting and challenging. I like the fact I am included as a member of the team helping deliver many parts of the programme. I like the fact my work will help lots of others with learning disabilities.

## Medical examiners in Sheffield

Since 1st April 2017 Medical Examiners in Sheffield have been working with LeDeR as a pilot project that notifies deaths of people with learning disabilities in that area. The aim is to assess whether the Medical Examiner system of reporting deaths provides us with more complete and comprehensive information than notifications of deaths from other sources. We plan to review this process at the end of the year.

## Priority Themed Reviews (PTR)

The LeDeR programme runs two panels to look at the reviews of some deaths in more detail. The priority themes this year are: 1) deaths of people aged 18 to 24 years and 2) those from a Black or Minority Ethnic group. We recently ran a consultation to gather views about the selection of a third theme. However, after discussion of a shortlist with HQIP, it has been agreed that the take-up of another theme will be postponed due to the additional pressures it would create for LeDeR delivery at local level at this time. Thank-you to all those who took part!

We will keep all comments received.

There has been a lot of progress over the last six months with the PTR aspect of the programme. We now have four panels of self-advocates trained, covering locations across England and we ran our first panel meeting in London in October. The professionals/ carers panel work has also got underway in the last couple of months. Both panels have provided excellent and varied additional insights into the reviews.

Thank-you to everyone involved.

## Are you a LeDeR reviewer or Local Area Contact? Would you like to become a LeDeR trainer?

The LeDeR programme aims for reviews of deaths of people with learning disabilities to become embedded in local systems across England. To maintain sufficient numbers of reviewers all areas will need to provide on-going LeDeR reviewer training. If you have experience of or an interest in training and would like to train new reviewers in your area, the LeDeR Training/ Quality Assurance team would be keen to work with you. If you would have the support of your manager to take this role on as part of your current job and would like to know more, please contact Jess Winkler at [jessica.winkler@bristol.ac.uk](mailto:jessica.winkler@bristol.ac.uk)

## Involvement of families – Local Area Contact Update Day on 22 November

Family carers who have experienced the death of a relative with learning disabilities have helped design and will participate in an Update Day for Local Area Contacts about engaging with families. It will take place in Birmingham on 22 November. Families and close friends are usually best placed to help make a good pen portrait of a person who has died, can often share otherwise unknown details relating to their death and give insights that are relevant in drawing up action plans. But there can be reluctance about contacting relatives soon after a person's death, fear about making things more difficult for them, wariness about being able to handle strong emotions that occur. Through discussion with bereaved family carers, hearing how others do similar work and exploring the support relatives and reviewers need, we hope the day will lead to increased, confident, effective work with family members.

## LeDeR YouTube channel

Our new YouTube channel is now up and running. We hope that it will become a helpful source of information for everyone involved in the learning disabilities mortality reviews. The channel currently features three playlists with videos: **Priority Themed Reviews**, explaining the work of a panel member and showing an example of a panel meeting; **Regional Workshops: "Taking forward the findings from mortality reviews into service improvements"** including Emily Lauer's presentations; **Video tutorials for reviewers**, a set of self-help video tutorials about the key functions of the web-based LeDeR review system with handy 'how to' tips and advice. We are also developing a similar set of video tutorials for Local Area Contacts, which will be published on the channel in due course.

<https://www.youtube.com/channel/UCBaTd285nA7u6GgIyA2241A>



### Notify a death

Anyone can notify us of a death online:

<https://www.bris.ac.uk/sps/leder/notification-system/>

or by phone:

0300 777 4774

