Learning Disabilities Mortality Review (LeDeR) Programme

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NEWSLETTER

June 2017

Improving the lives of people with learning disabilities

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

Roll-out progress

The LeDeR programme is rolling out the reviews of deaths of people with Learning Disabilities across NHS England by December 2017. All the required LeDeR steering groups in England have now been either identified or set up based on either a NHS sub-region boundary or using the Transforming Care Partnership boundaries. These groups oversee the LeDeR process in their area. There are currently 38 steering groups across NHS England. The programme has now trained more than 700 reviewers and over 40 Local Area Contacts. Notifications of deaths has surpassed the 500 mark and those eligible for review the 400 mark.

NHS England North

All deaths can now be reported and notified. 258 eligible reviews notified to date. Priority work to: enhance capacity by increasing the number of trained reviewers; maintain an active pool of reviewers; ensure that reviews are actively monitored.

NHS England Midlands and the East

Deaths can be notified and reviewed across the region from April 2017. 25 eligible reviews notified to date. Steering groups and governance arrangements set up. Approximately 100 people have received reviewer training. Information sessions have been particularly successful.

NHS England South

61 eligible reviews notified to date. All deaths in Wessex can now be notified and reviewed. South Central now has Local Area Contacts from each Transforming Care Partnership footprint area. South East and South West are being prioritised to establish the programme. Good progress made in organising steering groups using the Transforming Care Partnership footprint.

NHS England London

Notification of deaths from March 2017 and deaths being reviewed from beginning of May 2017. 44 eligible reviews notified to date. Priority work to identify organisation leads and more trained reviewers across London. On-line resource developed for London to support discussions and news updates.

http://www.bristol.ac.uk/sps/leder/about/roll-out-progress/

In the previous issue:

Roll-out progress in four regions
Involvement of people with learning disabilities & families
Focus on: Yorkshire & the Humber; the Wessex pilot
Debate in the House of Lords
Working with international colleagues
National Repository

www.bristol.ac.uk/sps/leder/news/newsletters/

Focus on

The pan-London LeDeR roll-out

From 1st May 2017 LeDeR has been rolled out across the whole of London, so that a LeDeR review will be undertaken when anybody with a learning disability in London dies. 56 notifications have been received to date since September 2016 and 148 reviewers have been trained across London. Organisational leads are being identified within NHS providers, Local Authorities and CCGs and they are being supported to set up local steering groups and local governance arrangements.

People with learning disabilities from the London region branch of the National Forum of People with Learning Disabilities have been consulted to gather their views on LeDeR; their London representative is an active member of the London LeDeR steering group.

NHS England is in the process of engaging with family carers to ensure that family perspectives are at the heart of LeDeR in London. If any London-based family carers or agencies that support family carers are interested in contributing their views on the LeDeR programme, we would be very pleased to hear from you. Please contact emily.handley1@nhs.net

Involvement of families

We want families to be involved in the LeDeR process and are being helped by lots of family carers to achieve this. We will be using four short YouTube films to help inform and encourage families and close friends to support LeDeR reviews. One will give personal accounts of taking part in LeDeR reviews of a relative's death, another an outline of learning and improvements that have already occurred because of action plans springing from reviews. Others will describe how the LeDeR programme works and feature the views of family carers when they have heard about it. The films will be launched in the autumn.

Learning Disabilities Mortality Review (LeDeR) Programme

Welcome to new staff!

In the last few months the LeDeR team has been joined by Regional Coordinators:
Robert Tunmore (South): r.tunmore@nhs.net
Maria Foster (North): maria.foster2@nhs.net
Louisa Whait (Midlands & the East): louisa.whait@nhs.net
Emily Handley (London): emily.handley1@nhs.net
Richard Jeffery (Programme Manager), Lindsey Allen & Jessica Winkler (Training & Quality Assessment Coordinators), & Dave Hanford (Information Officer Easy Read) have also recently joined the team.

Update on LeDeR training

The LeDeR team now has three trainers working to deliver training across England: Ade Murphy works in the Midlands and East, Lindsey Allen works with the North of England and Jess Winkler covers the South of England and London, so reviewer and Local Area Contact training is now taking place throughout England. Other new initiatives include refresher training and a Train the Trainer programme, which will ensure the continuation of learning disability mortality reviews. More than 700 reviewers are now trained and there has been great feedback from people who have attended reviewer training since it was updated at the beginning of this year. If you would like to become a LeDeR reviewer or find out more about our training packages, please don't hesitate to contact us: **leder-team@bristol.ac.uk**

Learning from Deaths programme

In December 2016, the Care Quality Commission (CQC) examined the way NHS trusts review and investigate the deaths of patients in England. Their report, called ***'Learning Candour and Accountability'*** found that many families do not experience the NHS as being open and transparent and that opportunities are missed to learn from deaths that may have been prevented.
In response to the CQC report, NHS Improvement and the Quality Board have published ***'National Guidance on Learning from Deaths'***. The guidance provides direction to acute, mental health and community trusts in relation to identifying, reviewing and investigating deaths and ensuring that learning is implemented. It clarifies that all deaths of people with learning disabilities aged four years and older should be subject to review using LeDeR methodology. For more information see: http://www.bristol.ac.uk/sps/leder/news/national-guidance-on-learning-from-deaths.html

Evaluation of LeDeR pilot sites

The LeDeR programme established regional pilot sites in 2016 to test out the methods and processes for undertaking reviews of deaths of people with learning disabilities. A huge thank you to all who contributed in the pilot site work.
The lessons learnt from the pilot sites have been shared at learning and sharing events in each region, and a report is now available on the LeDeR programme website: http://www.bristol.ac.uk/sps/leder/news/learning-from-leder-pilot-sites.html Key learning was gained in relation to local leadership, roles and responsibilities, decision-making, communication, confidentiality and training. Few people questioned why the LeDeR programme is needed; this meant that the energy and enthusiasm of the pilot sites could be channelled into making it happen. Once again, our thanks to all of you.

Priority Themed Reviews

We have had a lot of fun working with the Misfits Theatre company in putting together a video to be used in training self-advocates for the Priority Themed Review (PTR) panels. These panels will be used to gather the views of people with learning disabilities, by looking in more detail at the reviews of those who were aged 18-24 years when they died and/ or from a Black or Minority Ethnic group.
The video provides key information about the LeDeR programme and the role of the panel member. It reinforces key messages that we will convey in the training session: why the work is important, confidentiality, looking after yourself, and how the work will contribute to the desired outcomes of the LeDeR programme. The video will be available on our website and DVDs will be given to all panel members.
A huge 'thank-you' to the Learning Disabilities Advisory Group who helped us develop the processes for PTR panels and to the Misfits and Redweather productions for producing such a good end-product!

Regional workshops

We know that mortality reviews on their own are not sufficient to reduce health inequalities. What is essential is that we monitor the impact of mortality reviews, and how recommendations made may (or may not) lead to improvements in service provision and, over time, reduce premature mortality. To achieve this, the LeDeR programme is delivering a series of workshops to explore how we can take forward the findings of mortality reviews into service improvements; and monitor and report on the effectiveness of service improvements. Emily Lauer, the lead for similar work in the USA, will be contributing to the workshops. LeDeR steering group members are particularly welcome to attend. For more information see the LeDeR programme website
http://www.bristol.ac.uk/sps/leder/news/regional-impact-workshops.html

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