Learning Disabilities Mortality Review (LeDeR) Programme

Telephone: 0117 331 0686
Email: leder-team@bristol.ac.uk
Website: www.bristol.ac.uk/sps/leder/
Facebook: www.facebook.com/lederteam
Twitter: @leder_team

NEWSLETTER

November 2016

Improving the lives of people with learning disabilities

Welcome to the THIRD 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 piloting and then rolling out reviews of deaths of people with learning disabilities on a regional basis.

NHS England North

Since the last newsletter 178 people have completed the reviewer training in the region. Notifications from across the North region can now be made via the website or the confidential telephone line. The North East and Cumbria was the original pilot site for the LeDeR programme, which reported its work at a Learning and Sharing event in Durham on 19th July.

NHS England Midlands and the East

16 people have completed the reviewer training in the region since June. The pilot site for the Midlands and the East is Leicester, Leicestershire and Rutland, which is now receiving notifications of deaths. Two Learning and Sharing events have been held in Birmingham and Peterborough on 24th and 30th November.

NHS England South

The pilot site for the South is Wessex, which is now receiving notifications of deaths. 71 people have completed the reviewer training in the region.

NHS England London

Since June 51 people have completed the reviewer training in London. The pilot site for London is currently establishing governance and other arrangements for the work.

For a detailed roll-out plan please visit our website: http://www.bristol.ac.uk/sps/leder/about/roll-out-progress/

Involvement of people with learning disabilities and families

Our Advisory Group of people with learning disabilities has been helping us plan how we would support a person with learning disabilities coming to work with us in the office. We are also working with family members to develop some video clips about how reviewers can best involve families when reviewing a death. Thank you to all of you for your help.

In the previous issue:

Pilot sites: North East & Cumbria and Wessex.
Bereavement support for families.
Governance arrangements.
Data sharing agreements.
The LeDeR web-based platform.
Linking national mortality data.
National repository.
Factsheets.

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

Focus on

LeDeR in Yorkshire & the Humber

Yorkshire and the Humber is working in partnership with Speakup Self Advocacy, co-producing as much as possible and making sure people with learning disabilities are directly involved. As members of the Steering Group, Speakup self-advocates help produce materials in Easy Read and train and support the reviewers at their monthly meetings. At one session self-advocates described the kind of approach reviewers should take when working with people with learning disabilities who are bereaved. At another meeting, they helped reviewers to think about how to write person-centred pen portraits.

Speakup is also organising 6 events aimed at people with learning disabilities and their families and supporters. For further information about Speakup Self Advocacy visit http://www.speakup.org.uk/ Follow on Twitter @SpeakupSA

The Wessex pilot - key learning points

Initial review - one completed review demonstrated good practice in the care of the individual prior to their death and improved the care for others. The GP practice was pro-active in raising an issue with the CCG that a care provider had not been supporting people to attend the surgery for their annual health check. This enabled CCG commissioners to review the situation and clarify the requirements with the care provider. Patients are now supported to attend for their annual health checks.

Multi-agency review - one completed review highlighted good practice in the appropriate involvement of the Palliative Care Team, which supported the family to enable the individual to die at home. The review indicated that communication could be improved between the Community LD Team Case Coordinator (provider) and the LD Case Manager for the CCG (Commissioner). Work is now underway to improve links and understanding of roles.

Welcome to new staff!

In the last few months the LeDeR team has been joined by Melanie Avis (Programme Administrator) who is the main contact for programme roll-out queries and notifications of deaths of people with learning disabilities. Irena Holdsworth (Senior Programme Administrator), Lucy Brockbank (Programme Officer) and Ade Murphy (Training and Quality Assessment Coordinator) have also recently joined the team.

National Operational Steering Group

The national Operational Steering Group, chaired by Crispin Hebron at NHS England, has been meeting regularly, and has been focusing on governance issues, and national communication about the programme.

Factsheets

A series of factsheets have been recently developed or updated to support reviewers. Visit our website for: 'Guidance for the conduct of local reviews of the deaths of people with learning disabilities', 'Briefing Paper 7: Involving Families in the LeDeR Review Process', 'Briefing Paper 12: How reviewers will work with you after the death of your relative with learning disabilities', LeDeR Review Process/ Timeline Guideline.

The LeDeR team out and about

The LeDeR team have been out and about sharing information at events including the All Party Parliamentary Group meeting, the Learning Disabilities Nurses Continuing Professional Development day, and the national conference for the Palliative and End of Life Care of people with learning disabilities network.

Debate in the House of Lords

A debate about premature mortality of people with learning disabilities was led by Baroness Sheila Hollins in the House of Lords in October. Issues discussed in the debate were:

- Insufficient attention being paid to addressing the causes of premature deaths
- The need to mandate reviews of deaths of people with learning disabilities
- Core skills of professionals in communicating with, and supporting, people with learning disabilities to be improved
- Urgent action is needed to ensure that the learning from mortality reviews is embedded, so that no more people with learning disabilities die due to avoidable circumstances.

Working with international colleagues

We have been sharing information about our work with other researchers and practitioners from several different countries via webinars and at the recent IASSIDD World Congress in Melbourne. We are the only country that has a national programme of mortality reviews for people with learning disabilities and there is a lot of interest in our work from other countries.

National Repository

The repository of reviews into deaths and 'near misses' (serious incidents) pertaining to people with disabilities is growing. Taking in Safeguarding Adults Reviews (formally Serious Case Reviews), Serious Incident Reports and Ombudsman reviews from across health and social care the repository holds an anonymised summary of reviews published in England in 2015 and 2016. As the only national repository, it is a vital tool to share learning points and recommendations from the reviews.

If you are aware of any review that has been published and fits the criteria, please contact Fred Dunwoodie Stirton in the LeDeR team to add it to the repository: **fred.dunwoodiestirton@bristol.ac.uk**

Notification page update

Anyone can notify us of a death using this new secure notification page: **https://www.bris.ac.uk/sps/leder/notification-system/**