



Learning Disabilities Mortality Review (LeDeR) Programme



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NEWSLETTER

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Improving the lives of people with learning disabilities

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

What is the programme all about?

The Learning Disabilities Mortality Review (LeDeR) Programme will be leading on a number of projects to shine a light on the deaths of people with learning disabilities and make improvements in the care and support provided to them and their families. One of the key aspects of our work will be to support local areas in England to review the deaths of people with learning disabilities and to reflect on what had worked well, and what had not worked well with a view to improving practice where necessary

Why is the programme necessary?

We know that there is a significant gap between the average age at death of people with learning disabilities and the average age at deaths of people in the general population of England. We have some evidence about why this gap exists, but there are some aspects that are not fully explained. We also know that there is a gap between policy and practice guidance, and the care and support that some people receive. We need to look more closely at why this is so and how it affects people with learning disabilities and their families.

What progress have we made?

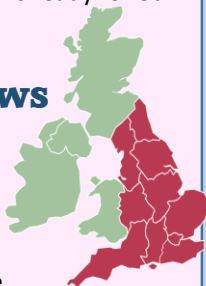
We have recruited our team and have been working hard to set up systems for our work. We consulted widely about the core information we will need to collect about each death of a person with learning disabilities. We are now testing our secure web-based reporting and review systems ready for our pilot sites.

Roll out of the local reviews of deaths

We are now starting to pilot the local reviews of deaths. Once we have learnt from the pilot sites what works well (and what doesn't work so well!) we will be rolling out the programme of reviews across England in a staged approach. We will work with a multi-agency Steering Group in each area to guide the local implementation and to monitor action plans that are written following each review.

We will update our website with further details of when each area will be starting to review deaths of people with learning disabilities.

www.bristol.ac.uk/sps/leder



Who are we?

Meet the team!

We are a team based within the Norah Fry research centre at the University of Bristol and we are working in collaboration with NHS England and HQIP. The team is led by Dr Pauline Heslop who has an established track record of delivering the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) based at the University of Bristol.

What are the aims of the programme?

The aim of the LeDeR Programme is to drive improvement in the quality of health and social care service delivery for people with learning disabilities and to help reduce premature mortality and health inequalities in this population.



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Who can notify us of a death?

Anyone can notify us including people with learning disabilities themselves, family members, friends and paid staff.

How can you notify us?

A simple, straightforward notification process will be adopted, making it easy for anyone to notify a death. Reporting will be via a 030 number or a secure web-based portal. A standardised form will be provided to guide you through the information we require.

What will a review of a death involve?

We are taking a proportionate approach to the local reviews of deaths of people with learning disabilities.

All deaths will receive an initial review. For this, the reviewer will consult with someone who knew the deceased person well, and will look at a relevant set of notes/records. The aim is for the reviewer to have sufficient information to:

- Provide a 'pen portrait' of the individual.
- Provide an account of the circumstances leading to death.
- Identify if there are any concerns about the death.
- Assess if any further learning could come from a fuller multi-agency review of the death.

If there is no indication that a full multi-agency review is required, the review will be completed. If there are grounds to suggest that a full multiagency review would be helpful, the local reviewer will arrange this. The aim of the multi-agency review is for those involved in supporting the person to collectively discuss and reflect on:

- The circumstances leading to the person's death.
- If there is any best practice in relation to the person's care that could be shared.
- What any potentially avoidable contributory factors to the death might be.
- What local learning and/or wider recommendations could be made.

Focus groups and family involvement

We have put people with learning disabilities and their families at the centre of the development and delivery of the Programme.

People with learning disabilities, family members and their relevant organisations (e.g. My Life My Choice, the National Valuing Families Forum) have been involved in helping us to develop our work plans and recruit our Programme team.

Family members have been involved with:

Helping to guide the Programme through membership at our Steering Group and Advisory Group, and on recruitment panels for programme staff.

Contributing to consultation groups about specific aspects of the Programme (helping to develop programme materials; planning the training content for local reviewers).

People with learning disabilities have been involved with:

Helping to guide the Programme through membership at an Advisory Group of people with learning disabilities, and representation at our multi-agency Advisory Group.

Contributing to consultation groups about specific aspects of the Programme (discussing the core data to be collected about deaths; helping to develop programme materials; planning the training content for local reviewers).

If you are interested in contributing to a consultation group, please do get in contact with us at leder-team@bristol.ac.uk.

The Learning Disabilities Mortality Review team



The Learning Disabilities Mortality Review Programme is on social media! We have a facebook page and a twitter page. Please 'like' or 'follow' us to get regular updates on the programme.