Learning Disabilities Mortality Review (LeDeR) Programme

Annual report 2015-2016

Summary

University of BRISTOL

NHS England

The Learning Disabilities Mortality Review (LeDeR) Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England.

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1. Introduction

This is the first annual report for the Learning Disabilities Mortality Review (LeDeR) programme. It details the progress made in establishing the programme in its first year during the 11 months from 1st June 2015 to 1st May 2016.

It covers the 'set up' activities for the new programme, the challenges faced in establishing a process for local reviews of deaths, and ways in which we are working through these challenges. It also provides information about the progress made in the series of additional projects and activities that the programme team have engaged with, alongside establishing a process for local reviews of deaths.

This is a complicated and challenging programme. Its delivery requires working across existing 'divides' (either perceived or actual), between health and social care, between primary and secondary care, and between generic and specialist services. The task for all these services is to find a 'home' for reviews of deaths of people with learning disabilities that can fit within existing systems, but because they are multi-agency by nature do not easily sit within any single system. It requires data sharing agreements across a range of agencies, and Secretary of State permission to enable the sharing of patient identifiable information without consent.

It is being established at a time of increased media scrutiny of avoidable deaths in general, and deaths of people with learning disabilities in particular. **It is important to recognise this programme as a service improvement initiative that is about learning lessons and making changes**, not a 'naming and shaming' exercise. As such, it has necessitated an approach that changes some hearts and minds to recognise the importance of prioritising the work in reducing premature mortality in people with learning disabilities. None of these are insurmountable challenges, but they have had the effect of slowing the progress that we would have liked to have made.

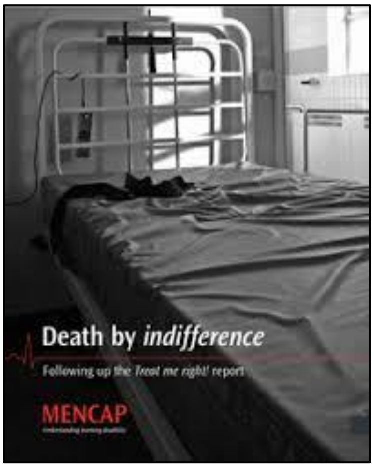
There has been a huge amount of good will and support offered to the programme for which we are very grateful. In particular, we would like to thank our first pilot site, the North East and Cumbria, for helping to find a way through some of the challenges and their steadfast determination and optimism about being a pilot site and learning what works. Led by Judith Thompson, the Chair of the Learning Disability Network in the region, they have worked with us constructively and cooperatively, and we are immensely grateful for their work.

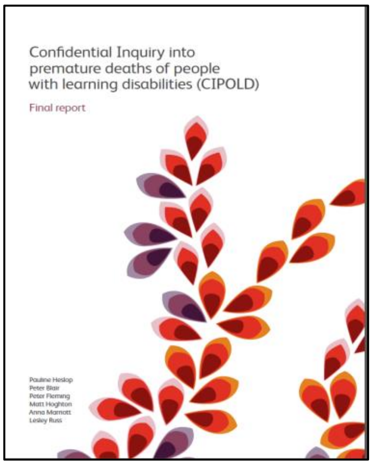
The learning that we are taking from this first pilot site is now helping our 'second wave' of pilot sites to test whether what works in one area of the country will do so in others. We would like to thank them all for helping us with this.

2. Background and context

Premature deaths in people with learning disabilities

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.





Recent calculations by Dr Gyles Glover at Public Health England, using data drawn from the Clinical Practice Research Database, indicate that more than three times the number of people with learning disabilities in England die each year than would be expected from general population mortality rates after allowing for their age and gender profile. (Glover et al. 2016). A large proportion of such deaths are considered to be avoidable through the provision of good quality health and social care.

3. Aims and objectives of the Learning Disabilities Mortality Review Programme

Aims and objectives of the LeDeR Programme

The overall 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.

It will do this primarily by supporting local agencies to conduct **reviews of the deaths** of people with learning disabilities and to take account of the **learning** that comes from these reviews in order to **improve** their **service provision**. It will also contribute to national and international evidence about mortality in people with learning disabilities.

Other objectives of the LeDeR programme are:

1. To influence practice change at individual, professional, clinician and allied health professional levels, such that it will contribute to improving service provision for people with learning disabilities and their families.

2. To influence change in policy and service provision at national level with Government, NHS England, Public Health England and the Local Government Association, such that it will contribute to improving service provision for people with learning disabilities and their families.

3. To support commissioning and service redesign by helping commissioners understand opportunities to improve service delivery, reduce variation and learn from best practice.

4. To encourage a move towards equality of treatment and parity of esteem for people with learning disabilities and help tackle the systemic contributors to the health and access inequalities they face.

The scope of the Programme

The LeDeR Programme will support reviews of deaths of people with learning disabilities aged 4 – 74 (inclusive) who are registered with a GP in England at the time of their death.

The Programme will support reviews of all deaths, irrespective of the cause of death or place of death.

Definition of learning disabilities

The LeDeR programme follows the definition proposed in 2001 by the white paper 'Valuing People'.

Learning disability *includes the presence of:*

- *a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with*
- *a reduced ability to cope independently (impaired social functioning)*
- *which started before adulthood, with a lasting effect on development.*

A person would not necessarily need to be registered on a GP's learning disability register for inclusion in the programme, provided the three criteria above are met.

4. Initial Implementation

Work on establishing the Programme started in June 2015. Initial work focused on the following:

Recruitment

Recruitment of the programme delivery team.

Governance

Independent Advisory group

The programme has been supported at national level by a multiagency Independent Advisory Group, chaired by Dr Dominic Slowie of NHS England. This group meets with the programme delivery team every six months.

Programme Steering group

The Programme Steering Group is chaired by Professor Peter Fleming. This group has continued to meet monthly since the inception of the Programme. Steering group members have additionally been involved in the programme's development over the course of the year, such as assisting with recruitment activities and providing expert scrutiny for briefing papers produced by the LeDeR programme team.

Programme Advisory groups

Two programme Advisory Groups have been established and each has met twice during the course of the first year.

- An Advisory Group of people with learning disabilities is comprised of 10 people with learning disabilities drawn from three organisations (Changing Our Lives - Sandwell; My Life My Choice – Oxfordshire; Bristol Healthy Living Advisors) plus the health representative from the National Forum.
- A multidisciplinary Advisory Group is comprised of 19 members representing a range of statutory and voluntary sector agencies and family members.

Consultation exercise

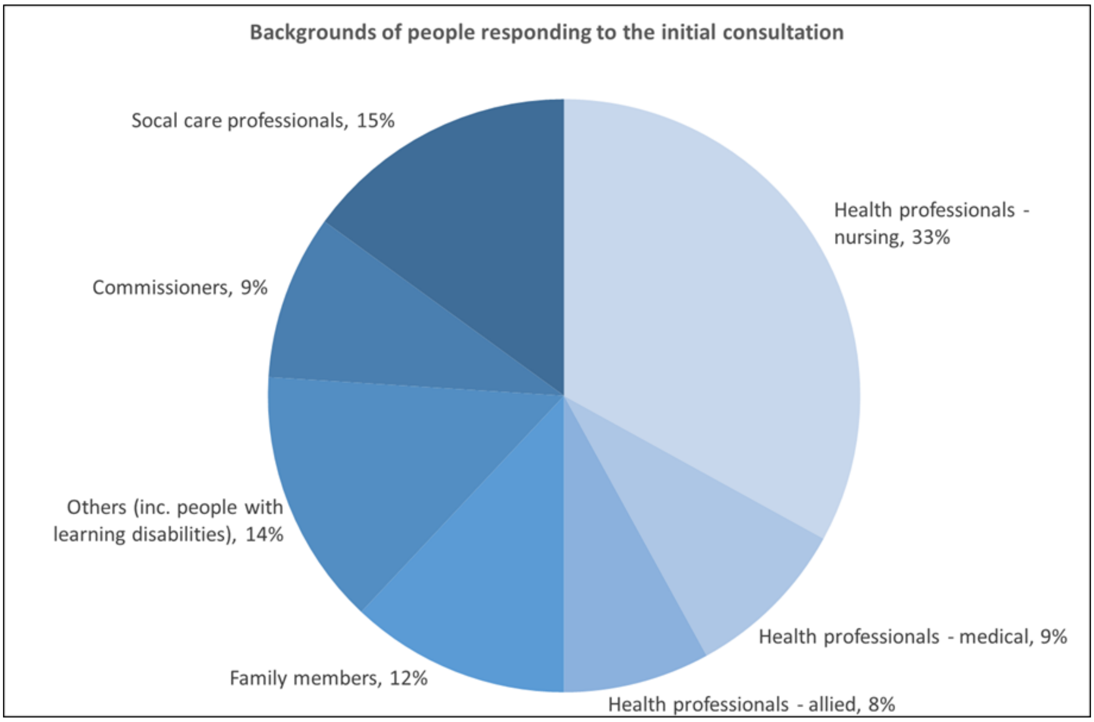
A formal national consultation with a wide range of professionals, policy-makers, people with learning disabilities and family members was launched regarding the process and content of the reviews of deaths of people with learning disabilities.

It had previously been agreed by NHS England that each death would receive an initial review; those deaths where any concerns had been identified, or from which it was thought further learning could come, would then have a full multi-agency review. In addition, a sub-set of deaths would be scrutinised in detail each year according to a priority theme. In the first year of the programme of reviews, all deaths of young people aged 18-24, and all deaths of people from Black and Minority Ethnic Communities would be subject to priority themed review. The reason for this is that existing research studies indicate that we know little about these deaths of people with learning disabilities. All of these deaths would receive a full multi-agency review with additional external panel scrutiny.

The consultation exercise sought to clarify:

- The core data to be collected at the notification of a death:
    - at the initial local review
    - at the full multi-agency review
    - where deaths meet the criteria for a priority themed review.
- The criteria for which deaths are judged to require initial review and which require full multi-agency review.
- The standards against which 'best practice' will be measured.
- The core definitions to be used in the programme.

The consultation was online, with paper copies and an easy read version available. More than 200 responses were received from respondents (or groups of respondents) from a range of backgrounds:



The consultation exercise was influential in helping us plan the process and content for the local reviews of deaths.

Development of web-based platform

The programme was required to establish a secure, web-based platform to handle the notification of deaths and the review process. Work on the development of the web-based platform for the programme commenced in September 2015 and the test system was ready for use in January 2016.

We conducted a focus group with potential ‘notifiers’ of deaths to check the availability of the data we are asking for, whether there were any significant difficulties in providing the data, and what it might feel like for a person to notify a death and how we could best support them.

The test system was then ready for use for notifications of deaths and to support the review process. It has been used during training events within pilot sites, and those who have practised testing the system generally find it very user friendly.

Information governance

The security of personal information is of vital importance to the programme. We have completed and submitted an NHS Information Governance Toolkit with associated documents and policies (Organisation National Code: EE133799-SPS-LDMRP). Our IG toolkit score is 91%.

The external link to our IG toolkit can be found here: **http://tinyurl.com/jre48b8**

Approvals for the work

Confidentiality Advisory Group

As soon as we knew the shape and content of the secure web-based platform, we made an application to the CAG for Section 251 approval for the LeDeR Programme.

Section 251 of the NHS Act 2006 allows the Secretary of State for Health to make regulations to set aside the common law duty of confidentiality for defined medical purposes. The Regulations that enable this power are called the Health Service (Control of Patient Information) Regulations 2002.

‘Section 251 approval’ refers to approval given under the authority of these Regulations. Section 251 approval enables the common law duty of confidentiality to be overridden to enable disclosure of confidential patient information for medical purposes where it was not possible to use anonymised information and where seeking consent was not practical. Responsibility for providing advice to the Secretary of State about Section 251 applications rests with the Health Research Authority Confidential Advisory Group (CAG)[1].

The application was made on 16th November 2015 (CAG reference: 16/CAG/0005) with final approval granted in June 2016.

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[1] For more information about Section 251 approval and the work of the Confidential Advisory Group see: http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/what-is-section-251/#sthash.kd4vxWzO.dpuf

5. The involvement of families and people with learning disabilities

The involvement of families

There are a number of ways in which families have been involved with the programme during its first year and they continue to be co-producers of the work:

- Families were consulted during the development of the tender for the work.
- As a member of the Steering Group.
- As members of the programme Advisory Group.
- We have recruited some family members to be on Priority Themed Review panels for the pilot stage of the programme.
- **12% of respondents to the online consultation about LeDeR's core data set were family carers.**

We have held four formal consultation groups with family members of people with learning disabilities.

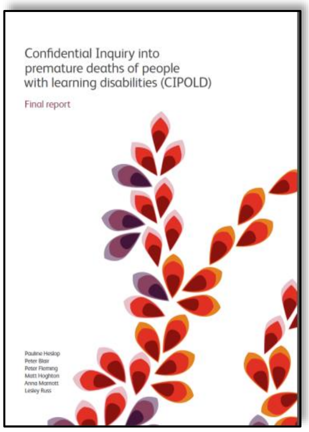
- **September 2015:** meeting in Birmingham with family carers from several different Black and Minority Ethnic (BME) communities to consider programme information leaflets and promotional materials.
- **November 2015:** meeting in Sheffield with family members to gain their views about the proposed training programme and materials for local reviewers. The group also included family members with employed positions in learning disability services or supporting family carers, so their views were drawing on wide ranging and multiple experiences.
- **March 2016:** consultation meeting with a Punjabi women carers group in Sheffield. The focus of the discussion was cultural aspects of caring for a person with learning disabilities, and issues the Priority Themed Review panels should take into account.
- **March 2016:** consultation meeting in Leicester with family members about cultural aspects of caring for a person with learning disabilities, and issues the Priority Themed Review panels should take into account.

We have provided updates to families as follows:

- An update report is given to every quarterly meeting of the National Valuing Families Forum. This means that regional representatives of family carers who sit on local partnership boards and other working groups active at local authority level, plus leads for national provider organisations with family carer support services, and representatives from the National Forum, are informed about the programme's work, and can ask questions and raise issues of relevance to its roll out.
- Updates have been fed into the (generic) Standing Commission on Carers meetings.

The involvement of people with learning disabilities

The inclusion of people with learning disabilities in the programme has been of central importance and they too continue to be co-producers of the work. During the first year of the programme, people with learning disabilities have been involved in the following ways:



Confidential Inquiry into
premature deaths of people
with learning disabilities (CIPOLD)

Final report

Pauline Heslop
Peter Blair
Peter Fleming
Matt Hoghton
Anna Marriott
Lesley Russ

- People with learning disabilities who had previously been involved with the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) were consulted during the development of the tender for the work. For more information about CIPOLD see Heslop et al. (2013) or http://www.bristol.ac.uk/cipold/
- The Advisory Group of people with learning disabilities has 10 members.

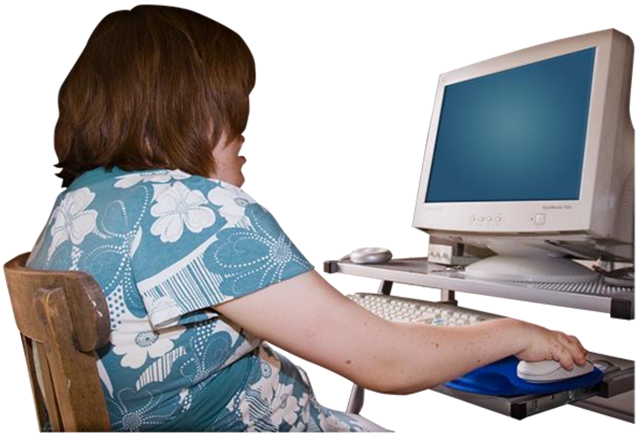
- We circulated an easy read paper version of the online consultation about LeDeR's core data set. A number of Partnership Boards and self-advocacy groups jointly and individually completed the consultation questionnaire. In order to allow sufficient time for people with learning disabilities to present their views, the consultation exercise was extended by six weeks.

- We have held **two formal consultation groups with people with learning disabilities**.

  The first was in **September 2015 in Birmingham** to find out **what information it would be important for us to collect about deaths**.

  The second meeting was in **March 2016 in Gloucester** and focused on what group members thought was **important for local reviewers to know about people with learning disabilities in general**.

- We are engaged in discussions with a Supported Employment agency in Bristol about the possibility of offering a work placement with the LeDeR team to a person with learning disabilities for one day a week from January 2017.



6. Piloting reviews of deaths

North East and Cumbria pilot site

Once the processes and systems for the local reviews of deaths had been established 'on paper', we started to work with the North East and Cumbria as the programme's first main pilot site.

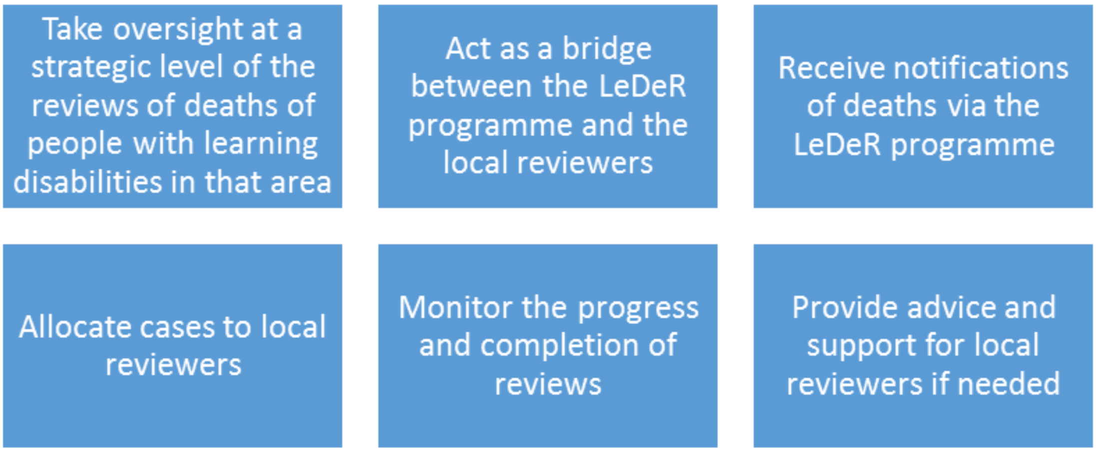
Initial discussions were held with the Chair of the Learning Disabilities Network in **November and December 2015**, with the North East and Cumbria becoming a **pilot site from January 2016**.

Steering Group

A sub-group of the Network formed the nucleus of the regional Steering Group for mortality reviews of people with learning disabilities. Additional representation was sought from under-represented groups.

Draft terms of reference for the Steering Group were developed by the LeDeR programme and have been amended to suit the purposes of the North East and Cumbria. Steering Group meetings have been held monthly since the start of the pilot.

Local Area Contacts



Take oversight at a strategic level of the reviews of deaths of people with learning disabilities in that area

Act as a bridge between the LeDeR programme and the local reviewers

Receive notifications of deaths via the LeDeR programme

Allocate cases to local reviewers

Monitor the progress and completion of reviews

Provide advice and support for local reviewers if needed

Once a review has been completed LACs receive completed review documents and action plans. In conjunction with Steering Group or any other agency, they ensure that appropriate action is taken, as required to help improve the care of people with learning disabilities (and their families) and to reduce premature mortality in this population. A template for a role description for the Local Area Contact was developed by the LeDeR team for use in the pilot site. To date a number of Local Area Contacts have been identified to work at a local level.

Local reviewers

Each locality in the region was asked to identify at least two people who may be interested in expanding their existing role to incorporate conducting local reviews of deaths of people with learning disabilities. A template for a role description for local reviewers was developed by the LeDeR team for use in the pilot site. Training days for local reviewers were then provided by the LeDeR team.

Capacity to undertake the work

Significant concerns have been raised locally about professionals' capacity to undertake reviews of deaths. Although we have taken a proportionate approach to the reviews, with each death receiving an initial review and only those meeting the required threshold receiving a full multi-agency review, it has been difficult to allay such concerns without accurate population-based data about expected numbers of deaths.

We have worked with Dr Gyles Glover at Public Health England to calculate, as best we can, the expected number of deaths in each region, taking into account as far as possible, the age/sex population data for each region, and data about people with learning disabilities on GP Quality and Outcomes Framework (QOF) registers, and national age/sex specific death rates for people with learning disabilities from the Clinical Practice Research Database.

In total, the **expected number of deaths of people with learning disabilities aged 4-74 each year in England is approximately 2,300**.

Deaths of children 0-17 years of age are already reviewed by the statutory child death review process; the LeDeR review process does not duplicate this but ensures that issues relating to a person's learning disabilities (if relevant) are considered and data required by the programme is collected.

Governance of the work

Both local and regional accountability and governance arrangements are required for the work. These will be located within existing recognised structures whenever possible.

Within the North East and Cumbria pilot site, the natural 'home' for the work has been agreed to be within the safeguarding framework. That is not to say that all deaths of people with learning disabilities are safeguarding issues – clearly they are not; rather the safeguarding framework provides an established multiagency way of working that aims to protect the health, well-being and human rights of individuals – an approach that the LeDeR programme takes in reviewing deaths of people with learning disabilities.

At regional level, Quality Surveillance Groups are emerging as the natural home for reporting the findings from reviews of deaths.

Data sharing requirements and permissions

Our application for Section 251 approval from the Confidential Advisory Group to enable the sharing of patient identifiable information across the LeDeR programme had been submitted but not approved by the time the pilot started, so the pilot sites needed to establish what existing data sharing agreements were in place, and how these would need to be supplemented with a specific data sharing agreement for the purpose of mortality reviews of people with learning disabilities. A template for a draft data sharing agreement was developed by the LeDeR team to support this aspect of the work.

Communications

Briefing papers have been developed by the LeDeR team to update a range of agencies and organisations.

The North East and Cumbria Steering Group communication strategy involved sharing information about the programme with a wide range of relevant stakeholders.

The communication strategy is now being expanded to include more information for the public (communication with the public was not prioritised before Section 251 approval was received as we wished to avoid deaths being notified before we were able to receive those details).

Aligning the programme with other investigations and mortality reviews

The purpose of the LeDeR reviews is not to hold any individual or organisation to account. Other processes exist for that, including criminal proceedings, disciplinary procedures, employment law and systems of service and professional regulation.

It is vital, if individuals and organisations are to be able to learn lessons from the past, that reviews are trusted and safe experiences that encourage honesty, transparency and sharing of information to obtain demonstrable improvements in service provision.

In order to do this in a timely manner and to avoid duplication, reviewers need to be clear where and how the LeDeR process links with other review or investigation processes. Other investigations or reviews may include, for example: Serious Case Reviews (SCRs), Safeguarding Adult Reviews (SARs), Safeguarding Adults Enquiries (Section 42 Care Act), Domestic Homicide Reviews (DHRs), Serious Incident Reviews, Coroners' investigations and Child Death Reviews.

Unlike many of these other review or investigation processes, the LeDeR Programme has no statutory basis; i.e. agencies are not mandated to participate in the review of a person's death. The key principles of communication, cooperation and independence are therefore of vital importance when working alongside other investigation or review processes, many of which would take precedence over the LeDeR review process.

In the LeDeR process the notification of each death is followed up by an initial review. This initial review includes a review of relevant case notes, a conversation with someone who knew the person well (family members or other key people), the completion of a pen portrait, timeline and action plan.

If this initial review identifies factors that indicate the potential for further learning from a more detailed review of the death then it will be followed up by a multi-agency review. The multi-agency review will include different agencies involved in the deceased person's life and care, scrutiny of further records in order to identify lessons learned, agree good practice and identify any recommendations for further action at a local level. The learning from all of these reviews will be collated in a national reporting system that complements the learning from other investigations and mortality reviews.

Priority Theme Reviews

Priority Theme Reviews (PTR) are a subset of anonymised reports of deaths which have been subject to multiagency review and are then reviewed externally by specialist reviewers. In Year 1, deaths subject to Priority Theme Reviews are those of young people with learning disabilities aged 18-24, and those of people from Black and Minority Ethnic (BME) communities.

Consultation events have taken place with key stakeholders, including people with learning disabilities and families from black and minority ethnic communities, to enhance awareness of some of the issues faced by BME communities.

We are establishing two 'pools' of independent reviewers to scrutinise the deaths of people with learning disabilities whose deaths are subject to priority theme review during the pilot stage.

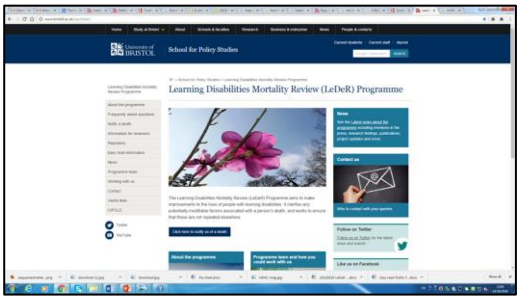
Local Reviewer Training

We have developed and delivered a one-day training course for local reviewers of deaths of people with learning disabilities. The purpose of the training is to enable reviewers to feel skilled, confident and competent to undertake reviews of the deaths of people with learning disabilities aged 4-74.

It aims to enable reviewers to identify any potentially avoidable factors that may have contributed to a person's death and develop plans of action that individually or in combination, will guide necessary changes in health and social care services in order to reduce premature deaths of people with learning disabilities.

In order to support the reviewers on an ongoing basis, a series of additional resources have been developed which are available on the LeDeR website. These include:

- A local reviewer guide which outlines the whole review process in detail.
- A handy hint guide on what to include in a pen portrait.
- Step by step illustrated guides on how to use the LeDeR Web based platform.
- A series of factsheets and briefing papers which provide information on current policy and best practice on key topics, e.g: legislation, supporting people with learning disabilities, medical conditions and interventions.



Priority Theme Reviewer (PTR) training

The PTR training for family carers and professionals commenced in March, with two half day training events delivered to twenty people. These were held in Bristol and Sheffield.

The training for people with learning disabilities who will be acting as reviewers is currently in development and will include a half day training for the reviewers and their supporters, a series of training resources in easy read format, and a video of the training.

7. Additional projects

In addition to supporting the local reviews of deaths of people with learning disabilities, the LeDeR programme is undertaking a number of related additional projects.

Analysing national data

Our work for this project has involved supporting Dr Gyles Glover at Public Health England by discussing, interrogating and making sense of linked data from the Clinical Practice Research Datalink database. This identified people diagnosed by their GP as having learning disabilities and registered with one of several hundred participating general practices covering approximately 5% of the population of England. Linkage to national death certification data allowed the derivation of linked population and mortality data for people with and without learning disabilities, overall and by cause.

We have jointly written and submitted a paper to the Journal of Intellectual Disability Research. This is now available in 'early view' following peer review (Glover et al. 2016).

Our findings indicated that mortality rates for people with learning disabilities were significantly higher than for those without. The all-cause standardised mortality ratio (SMR) associated with learning disabilities was 3.18. Life expectancy at birth was 19.7 years lower than for people without learning disabilities.

Circulatory and respiratory diseases and neoplasms (cancers) were the three most common underlying causes of death. Avoidable mortality analysis showed a high proportion of deaths from causes classified as amenable to good medical care.

International comparison to areas for which data have been published in sufficient detail for calculation of directly standardised rates suggest England may have higher death rates for people with learning disabilities than areas in Canada and Finland, and lower death rates than Ireland or one US state.

Repository for anonymised reports pertaining to people with learning disabilities

We are establishing a repository for anonymised reports pertaining to people with learning disabilities from a variety of sources. Recent criticisms of Serious Case Reviews and Child Death Reviews highlight that the same recommendations tend to be made time and again, and that there is little convincing evidence that the learning from each review is shared beyond those involved in the case itself.

We are not limiting the repository to case reports relating to the deaths of people with learning disabilities. Important learning can also come from reflecting on 'near misses' or on the circumstances in which people with learning disabilities are exposed to harm.

Contacts were made and requests sent to local Adult Safeguarding Boards and NHS trusts in England for Serious Case Reviews (now Safeguarding Adult Reviews) and Serious Incident Reports pertaining to people with learning disabilities that had taken place since January 2015.

We also reviewed all Ombudsman reports since January 2015 and extracted information about cases involving people with learning disabilities.

The resulting reports were summarised and anonymised to form the basis of the repository. An associated document identifies key learning points and recommendations that have been identified from the case reports.

The repository is now available on the LeDeR programme website at: http://www.bristol.ac.uk/sps/leder/repository/

Mapping the provision of reasonable adjustments for people with learning disabilities

To inquire whether Clinical Commissioning Groups (CCGs) are paying sufficient attention to the need to provide reasonable adjustments for people with learning disabilities, Freedom of Information (FOI) requests were sent to all CCGs in England. These requested that CCGs provide a response to the question:

> *'What is the exact wording contained in your contracts with providers to ensure the provision of reasonable adjustments for people with learning disabilities is embedded in practice?'*

Many respondents commented that they used the wording in the NHS standard contract with their service providers. However just 12% provided actual details as to how they ensure reasonable adjustments are embedded in practice through their contracts with providers. Of these, the use of auditing and quality assurance was the primary method of ensuring compliance in relation to reasonable adjustments that was evidenced by CCGs.

In addition to this work, the identification and provision of reasonable adjustments will be scrutinised at each case review, and any learning points and recommendations related to these included in agency action plans.

A project to improve death certification in people with learning disabilities

The inconsistency of recording that a person had learning disabilities on their cause of death certificate has been debated for a number of years. This project aims to improve the recording and identification of learning disabilities on cause of death certificates, and to support more accurate recording of causes of death, including contributory causes, in people with learning disabilities.

Work is underway on a briefing paper for the Chief Coroner to highlight the issue and the need for clarity. This is being supported by a review of existing literature on the subject, and analysis of data from CIPOLD providing examples of inconsistencies.

8. Looking forward

The delay in securing Section 251 approval impeded the original programme so the team has produced a revised plan which will see the programme delivering by June 2018. The refreshed delivery plan is based on introducing at least one new pilot site in each of the NHS Regions - South, Midlands and London. This, along with the pilot site running in the North, will allow learning from pilot site involvement to be more evenly spread across England.

In each pilot site there will be a three month preparation period, with support from the central team to identify key roles, train local reviewers and ensure governance systems are in place for the reviews. The LeDeR team will then work in each area for a four month period as the site starts reviewing deaths.

Prior to the wider roll out of reviews in each Region, a regional 'learning and sharing' event will be held to share information about the local reviews of deaths, reflect on what has been learned from the pilot(s) and what is needed to streamline the process to make wider roll out successful. Following each 'learning and sharing' event, the programme of mortality reviews would be rolled out across the region as a whole.

In light of the programme's experience thus far, and following recommendations from the National Operational Steering Group, we are in discussion with NHS England about increasing the number of Regional Coordinators to four. Having a Coordinator based in each NHS region will make it easier to embed the programme within existing regional structures whilst retaining LeDeR's national remit.

9. Acknowledgements

There are many people whom we would like to thank for their support and help during the first year of the LeDeR programme. In particular we would like to thank:

- NHS England, particularly Jeff Featherstone, Matthew Fagg, Hazel Watson and Crispin Hebron
- Healthcare Quality Improvement Partnership
- Members of the Independent Advisory Group chaired by Dr Dominic Slowie
- Members of the LeDeR Programme Steering Group chaired by Professor Peter Fleming
- Members of the LeDeR Programme Advisory Groups
- All of the family members and people with learning disabilities who attended any of the LeDeR consultation events
- Everyone who responded to our consultation exercise, and to the focus group attendees from the Kent and Medway Learning Disability Community of Practice
- The North East and Cumbria Learning Disability Network, and in particular Judith Thompson and Kirsty Bell
- Those working to implement the LeDeR programme in the pilot site areas
- The Improving Health and Lives learning Disability Observatory
- The National Valuing Families Forum

10. References

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For more information about the LeDeR programme please contact:

Pauline Heslop,

Programme Lead LeDeR

University of Bristol, School for Policy Studies

8 Priory Road, Bristol BS8 1TZ

Tel: 0117 3310686

Email: leder-team@bristol.ac.uk

Web: www.bristol.ac.uk/sps/LeDeR