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# Norfolk and Waveney Learning Disability Mortality Review (LeDeR) Programme

## Annual Report for April 2019 to March 2020

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## 2. Introductions from the Learning Disability Mortality Review Steering Group Chair and Co-Chair

Sarah Jane Ward

*Chair, Learning Disability Mortality Steering Group*
*Associate Director of Quality in Care NHS Norfolk and Waveney Clinical Commissioning Group.*

2.1 Welcome to the annual report of the Norfolk and Waveney Learning Disability Mortality Review (LeDeR) Steering Group. This report outlines the work during the period 1 April 2019 to 31 March 2020. You will find information on the LeDeR activity, functions, processes and analysis. It reviews the recommendations from the LeDeR reviews undertaken in Norfolk and Waveney from June 2017 till the end of March 2020.

2.2 It has been evidenced that people with a Learning Disability die younger than the population as a whole. Overall, people with learning disabilities currently have a life expectancy at least 15 to 20 years shorter than other people.

2.3 This year has seen continued commitment to ensure effective communication and good working relationships. The Norfolk and Waveney LeDeR Steering Group have been working hard to increase the number of reviews outstanding over the past year, employing a part-time reviewer in 2019 in addition to the current reviewers and access to external reviewers. It is through this scrutiny and constructive challenge that we will continue to jointly work to improve services across Norfolk and Waveney. We would also like to give thanks to Alison Leather as the outgoing chair of the steering group and previous LeDeR CCG lead and wish her well in her new role.

**Final thoughts.**

"If your programme prevents the loss of one more vulnerable adult's life or ensures they are treated with empathy and dignity you may use any information. It cannot bring back my son, but it can help others." (quote from a father reported July 2020 National Bristol LeDeR report).

Andrew Borrett

*Co-Chair Learning Disability Mortality Steering Group*
*Expert by Lived Experience*

2.4 Hello my name is Andrew Borrett I am an Expert by Lived Experience as I have a learning disability and autism.

2.5 I am the Co-Chair with Sarah Jane Ward in Norfolk and Waveney. I have been in this position for four years. I am proud that I have this role and want to see other people being given the opportunity to take up this role across the country.

2.6 It is very important that peoples' deaths are reported. Sadly, I know people with learning disabilities who have reported their own friend's death. Don't be afraid to report a death – as hard as it is they might get missed otherwise.

2.7 I have sat and listened to the investigations on people's deaths and helped health professionals think about how and why things happened that way for that person. I use my lived experiences to question whether it was right and fair. We need things to change for the better.

2.8 I have had a number of friends that have died too early and I remind professionals that we are not just a number or a case but we are brothers or sisters, a mum or dad, son or daughter. I am always moved by how the investigating officers worked hard to find out details of who the person was, how they lived their life, interests and who they were.

2.9 The investigators are committed to getting information from different health and social care settings and that is hard work but they don't give in. It's important to get it right not just to rush the investigation. Each case needs time to do it properly. That shows respect for the person who has died.

**Final thoughts:**

I would like to personally thank all the investigators as I know they are doing this on top of their day-to-day work which is truly amazing.

**Things I have changed:**

3.0 I have met with ACE advocacy in Suffolk and looked at the Easy Read health check information they have developed. This helps people to be the expert in their own health. I am pleased to hear that NHS Norfolk and Waveney CCG has funded the printing of these health check materials. I am excited to hear ACE Anglia Suffolk are partnering up with Learning Disability England, Care England and Race Equality Foundation to deliver a national LD Annual Health Check Campaign. I hope I can support this with members, friends and colleagues from Opening Doors.

3.1 In the last year we have been involved in research with Healthwatch talking to more than 80 people with learning disabilities across Norfolk and Waveney, talking to them about their experiences of using health books and hospital passports. I feel that we need to hear peoples voices more about their experiences of health services and listen to what needs to change. This will help us to have a better quality of health care and a longer life like everyone else.

## 3. Background

3.1 Since the 1990s, there have been a number of reports and case studies which have consistently highlighted that, in England, people with learning disabilities die younger than people without learning disabilities. The Confidential Inquiry of 2010-2013 into premature deaths of people with learning disabilities (CIPOLD) reported that for every one person in the general population who died from a cause of death amenable to good quality care, three people with learning disabilities would do so.

3.2 Overall, people with learning disabilities currently have a life expectancy at least 15 to 20 years shorter than other people. This is unequivocal evidence that demands additional scrutiny be placed on the deaths of people with learning disabilities across all settings. This is managed by The Learning Disabilities Mortality Review (LeDeR) programme, commissioned by Healthcare Quality Improvement Partnership (HQUIP) on behalf of NHS England.

3.3 The programme receives notification of all deaths of people with learning disabilities, and supports local areas to conduct standardised, independent reviews following the deaths of people with learning disabilities aged over four years of age. These are conducted by trained reviewers. The purpose of the local reviews of death is to identify any potentially avoidable factors that may have contributed to the person's death or any gaps in provision leading up to their death and to 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.

3.4 In June 2017 South Norfolk CCG established a Learning Disability Mortality Review Steering group on behalf of the 5 Norfolk and Waveney CCGs. The purpose of the group is to support the LeDeR programme by:

- Working in partnership with the Bristol team;
- Working in partnership with stakeholders to ensure proportionate representation from across all sectors;
- Locally guide the implementation of the LeDeR programme;
- Support the review of all deaths of people with learning disabilities;
- Assist with interpreting and analysing data from local reviews;
- Monitor actions plans;
- Agree protocols for information sharing.

## 4.0 Process

4.1 The administration of the Norfolk and Waveney Learning Disability Mortality Review Steering group process and the role of the Local Area Contact (LAC) is provided by NHS Norfolk and Waveney Clinical Commissioning Group and is chaired by the Associate Director of Quality in Care.

4.2 The standardised review process is detailed in appendix 1.

Anyone can notify the LeDeR team at Bristol of a death of someone with a learning disability by using the online form http://www.bristol.ac.uk/sps/leder/notify-a-death/.

4.3 The case is then allocated to the relevant locality (via the LAC) for allocation of a reviewer. In Norfolk and Waveney area, the team then request information from all healthcare providers involved in the care of the deceased to provide a baseline of information for the reviewer.

4.4 When a death of a person with learning disabilities occurs, mandatory review processes or investigations (such as Safeguarding Adult Reviews, Structured Judgement Reviews, Child Death Reviews, and coroner's/police investigations) need to take precedence. LeDeR Reviewers need to ensure that a coordinated approach is taken to the review of the death in order to minimise duplication and bring in the learning disabilities expertise.

## 5.0 Government response to the Third National LeDeR Annual Report 2019. Published February 2020.

5.1 **Recommendations**:

- Consider designating national leads within NHS England and local authority social care to continue active centralised oversight of the LeDeR programme.
- **Support for Clinical Commissioning Groups** - NHS England to support Clinical Commissioning Groups to ensure the timely completion of mortality reviews to the recognised standard.
- **Identifying young people at transition** -There should be a clear national statement that describes, and references to relevant legislation, the differences in terminology between education, and health and social care so that 'learning disability' has a common understanding across each sector and between children's and adults' services.
- **Listening to families** - The 'Ask Listen Do' programme supports organisations to learn from and improve the experiences of people with a learning disability, autism or both.
- **Priority programmes of work needed** - agree that key themes identified in LeDeR reports should inform the prioritisation of programmes of work.

## 7.0 Local Activity

7.1 For the time period of this report **72** notifications were received. (1 April 2019 to 31 March 2020).

7.2 Total notifications for children and young people is **5** (April 2017 until 31 March 2020)

To Note**:** The deaths of children up to the age of 18 are reviewed by the Child Death Overview Panel (CDOP) these are not subject to an additional LeDeR review. Any possible learning and recommendations related specifically to learning disabilities are discussed and submitted to relevant partners.

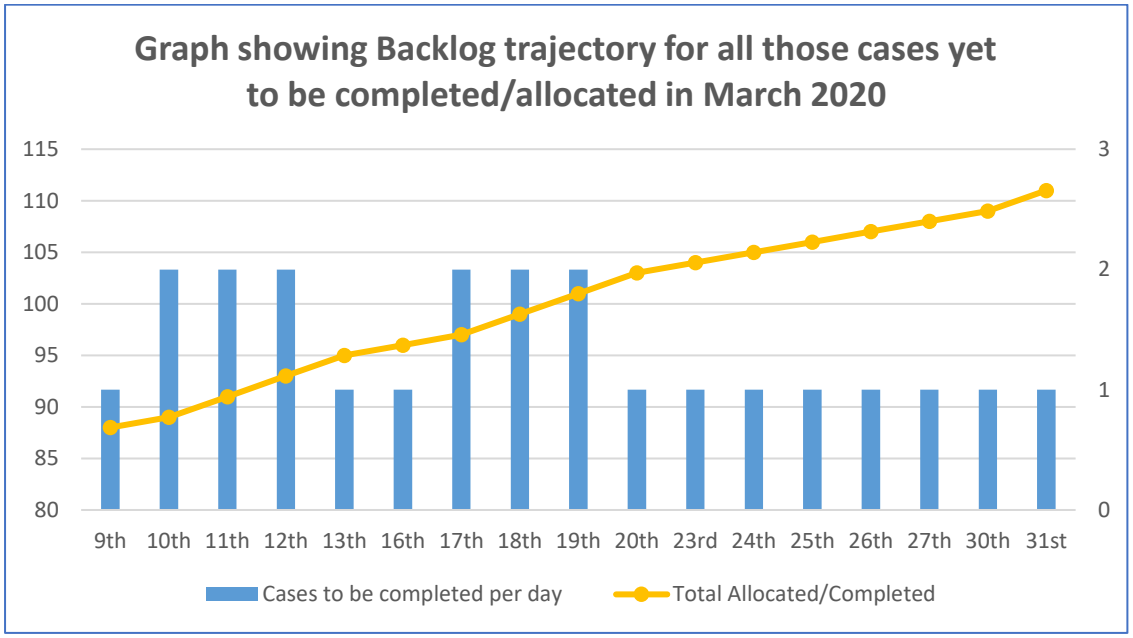
7.3 For Norfolk and Waveney the median age at death was **62** compared to the England average of **61.**

**Place of death**:

Hospital 55% Home 36% Other 9%

To note fewer than five Black and Minority Ethnic (BME) people have been notified in Norfolk and Waveney area in the last 12 months.

7.4 Within Norfolk and Waveney during 2019/20 there was an increased focus on completing the outstanding reviews. The graph below shows the progress in March 2020




7.5 With the introduction of the LeDeR e-learning platform, it is easier for reviewers to access training. Norfolk and Waveney CCG have recruited a part-time reviewer and as well as local reviewers there are also some external reviewers available to address the backlog of reviews.

7.6 **Local action being taken;**

- Since the Covid-19 pandemic, many of the reviewers were deployed to front line services, however the part-time reviewer has continued with the reviews allocated to them.
- A process of turning 'learning into action' is led by the local multi-disciplinary group, whose work programme is based on the Norfolk and Waveney Learning Disability Quality Improvement Plan. This group is co-chaired by Expert with Lived experience supported by the advocacy group. (see point 8 below)

7.7 The recommendations by the reviewers are included in the actions for the LeDeR steering group and are incorporated into the Learning Disability Quality Improvement Plan (see point 8 below.)

7.8 **Some themes identified from the completed local reviews in 2019/20:**

- Application and understanding of the Mental Capacity Act and reasonable adjustments;
- Access to cancer screening;
- Multi-agency working;
- End of life care planning.

7.9 **Achievements to date:**

- **Constipation** (identified as an area requiring improvement both in National and local LeDeR reviews**)** Bowel care standards developed for care/residential settings and a training session delivered to over 70 care staff in February 2020, this received very positive feedback. Planning to pilot the standards in some care home/residential/supported living settings in 2020/21 and to offer further training.
- **Pneumonia Risk** - as part of the winter flu campaign 2019/2020 across Norfolk and Waveney**,** easy read information regarding flu vaccination was shared and primary care and community staff encouraged people who had a learning disability to attend for a flu vaccine. This will be repeated in 2020/2021 as part of the winter flu campaign.
- **Dysphagia** - a multi-disciplinary group locally is in place looking at service improvements required. Any learning from the national dysphagia working group will also be considered.
- A Norfolk and Waveney Learning Disability Quality Improvement Plan has been written which includes the local and national recommendations, and updates are provided to the LeDeR steering group**.**
- Regular newsletters on LeDeR learnings from reviews are sent to the CCG which are forwarded to all steering group members for wider distribution. Leaflets from the National Team in Bristol, such as the management of constipation, dysphagia and

aspiration pneumonia are shared with our main providers, General Practices and care homes.

### 7.9 Priorities for 2020/21

- Continuing to address the backlog of reviews.
- Bowel care guidelines to be piloted in some care homes. Further training to be provided.
- Flu campaign for 2020/21
- Mental Capacity Act / reasonable adjustments looking to hold a joint multi-agency training event with the Safeguarding Adult Board in 2021.
- Access to cancer screening.
- Annual health checks.
- To explore use of RESTORE 2 to identify deterioration in individuals within care/residential settings as part of the enhance care home framework.
- Develop Learning from Covid-19 related deaths and identify any immediate learning from the care and circumstances of those people who died.

**8.0 Themes and priority areas for 2020/21. (Norfolk and Waveney Learning Disability Quality Improvement Plan 2019-2022 produced based on national and local learning from the LeDeR reviews.)**

| **Norfolk and Waveney LeDeR reviews (areas of learning identified 2019/2020)** | **Recommendations from National and local LeDeR Reports published May 2018 and May 2019** | **Actions included in a quality improvement plan for 2020/2021** |
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| Pneumonia risk. | 1) Focus on increasing the uptake of the flu vaccine among people with a learning disability alongside other at risk groups through a targeted awareness campaign. | **1.** Easy read information to made available across the system as part of the winter flu campaign.<br>**2.** Staff being encouraged to ensure people who have a learning disability have a flu vaccine. |
| **Norfolk and Waveney LeDeR reviews (areas of learning identified 2019/20)** | **Recommendations from National and local LeDeR Reports published May 2018 and May 2019** | **Actions for Primary Care and CCGs 2020/2021** |
| Annual Health Check. | 1. NHS England to report progress on uptake of Annual Health Checks to DHSC via Clinical Commissioning Group Improvement and Assessment Framework. | 1. Awareness raising re importance of Annual Health Checks.<br>2. National target of 75 % people who have a learning disability to have an annual health check.<br>3. Primary care to implement quality outcome framework in relation to annual health checks. |

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| Constipation. | 1. The NHS will launch a national campaign to promote awareness around the risk of constipation including how it can be prevented, recognised and treated to better support families, carers and staff who work with people with a learning disability | 1. Learning Disability Learning into Action Group established and has developed bowel care guidelines for care home/residential home /supported living settings.<br>2. NHSE Easy read constipation information circulated to providers.<br>3. Looking to pilot the bowel care guidelines in some care home/residential homes in 2020/2021<br>4. To provide further training to care settings to be co-delivered with Experts with lived experience. |

| **Norfolk and Waveney LeDeR reviews (areas of learning identified 2019/20)** | **Recommendations from National and local LeDeR Reports published May 2018 and May 2019** | **Actions to be included in a quality improvement plan for 2020/21** |
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| Reasonable adjustments, record the adjustments that are required and regularly audit their provision | 1. Implement NHS Digital Reasonable Adjustment Project rollout and as part of this align with the LHCREs to ensure the same information is being used in both. NHS Digital/NHS England, 2020 | 1. Mandatory learning disability awareness training should be provided to all staff, delivered in conjunction with people with learning disabilities and their families.<br>2. Ensure organisations are regularly auditing their provision of reasonable adjustments. |

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| | | 3. To explore possibility of further training on reasonable adjustments being co-delivered with Experts with Lived Experience to primary care settings in 2020/2021. |
| Dysphagia assessments and training. | 1. Recognising deteriorating health or early signs of illness in people with learning disabilities and minimising the risks of pneumonia and aspiration pneumonia. | 1. Dysphagia group established being led by the acute hospital. Planning to develop on pathway across the system and develop a training package for staff.<br><br>2. To link with the National learning into action group that is currently looking at this area and review dysphagia training and assessment across the local system, ensuring reasonable adjustments are made and easy read information available.<br><br>3. To explore possibility of introducing RESTORE2 training in care home/residential settings. |

| **Norfolk and Waveney LeDeR reviews (areas of learning identified 2019/20)** | **Recommendations from National and local LeDeR Reports published May 2018 and May 2019** | **Actions to be included in a quality improvement plan for 2020/21** |
|---|---|---|
| Strategic approach to be taken for the delivery of learning disability mortality reviews with Executive | 1. Consider designating national leads within NHS England and local authority social care to continue active centralised oversight of the LeDeR programme. | 1. The CCG to ensure LeDeR reports are completed within six months and monthly reporting to NHSE/I against trajectories. |

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| level leadership and ownership across all providers and health and social care commissioners. | 2. NHS England to support Clinical Commissioning Groups to ensure the timely completion of mortality reviews to the recognised standard. | 2. To ensure the learning is included within the actions for the steering group and the learning into action group.<br>3. New N&W LeDeR framework produced . |
| **Norfolk and Waveney LeDeR reviews (areas of learning identified 2019/20)** | **Recommendations from National and local LeDeR Reports published May 2018 and May 2019** | **Actions to be included in a quality improvement plan for 2020/21** |
| Knowledge and correct application of the Mental Capacity Act | 1. Local services must strengthen their governance in relation to adherence to the Mental Capacity Act, and provide training and audit of compliance 'on the ground' so that professionals fully appreciate the requirements of the Act in relation to their own role. | 1. MCA training and monitoring required across the system.<br>2. Multi-agency Safeguarding event to be planned to include MCA. |
| End of life care | 1. The Department of Health and Social Care, working with a range of agencies and the Royal Colleges are to issue guidance for doctors that 'learning disabilities' should never be an acceptable rationale for a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order, or to be described as the underlying or only cause of death on Part 1 of the Medical Certificate Cause of Death.<br>2. People with LD should be fully informed of conditions and diagnoses particularly those that are life limiting to enable involvement in EOL care planning. Best interest decisions | 1. Letter sent in 2019 to all Chief executives/Director Nurses informing them that 'downs syndrome' is not a rationale for DNACPR-providers to report action taken via quality forums.<br>2. To be included as part of the actions for the LeDeR steering group. |

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| | may need to be in line with the MCA in that they incorporated patient preference particularly for EOL planning. | |
| Cancer screening | 1. Screening programmes should identify patients with learning disabilities in advance and ensure that<br>a) their correspondence is accessible<br>b) them make adjustments in terms of following up/supporting understanding<br>c) they consider mental capacity in cases in which a patient has an impairment of the mind or brain as per mental capacity act 2005 | 1. To be actioned by the LeDeR steering group working collaboratively with organisations.<br>3. Learning into action group along with support from the Experts with Lived Experience to prioritise improving access to cancer screening for 2020/21. |

## 9.0 Conclusion

9.1 The third year of the National Learning Disability Mortality Review process has been identified as a well-established process. There have been challenges with use of the LeDeR system, and capacity of reviewers to complete the work. In addition, other statutory processes such as structured judgement reviews (which are required to be completed within three months) create an unavoidable delay in the LeDeR review timescales. However, the local reviewers and the LeDeR steering Group members remain determined to see improvements in care for people who have a learning disability.

9.2 The NHS Long Term Plan makes a commitment to reducing the premature mortality of people with a learning disability and the continuation of the LeDeR reviews. For the CCG there will be a continued focus on improving the number of reviews completed.

9.3 We value the expertise that the Experts with Lived Experience provide to both our steering group and learning into action group. It is important to remember particularly in these challenging times that each loss was a person and it is important that we continue to learn and improve services for those that we support now.

**Appendix one – National LeDeR review process**