

Learning Disabilities Mortality Review (LeDeR) programme

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LeDeR, COVID-19 and SAGE

Three important reports were published on 12th November concerning the deaths of people with a learning disability during the COVID-19 pandemic.

1. The LeDeR team's analysis of completed reviews of deaths of people with learning disabilities who died with COVID-19. We wanted to understand the reasons for the increased rate of deaths during the pandemic and what recommendations reviewers suggested. Our report, including an easy read version, is available [here](#).

Key findings and conclusions are:

- There is a striking difference in age at death between COVID-19 deaths in the general population compared with people with learning disabilities. Just four per-cent of LeDeR deaths were aged 85 and over; in the general population of England and Wales, 47% of deaths from COVID-19 were in people aged 85 years and over.
- Of those who died from COVID-19, 37% had all three symptoms of cough, fever or difficulty breathing; 39% had two of the symptoms and 21% had one of these symptoms. No one reported a loss of sense of smell or taste, suggesting that this symptom is more difficult to identify in people with learning disabilities than in the general population so should not be relied on.
- There were four main areas where the quality of care was deficient:
 - Access to timely and appropriate healthcare, particularly the responsiveness of NHS111 (both the timeliness of response and the quality of advice given), difficulty in accessing COVID-19 testing, and lack of access to specialist learning disability services.
 - The provision of reasonable adjustments.
 - The recognition of deterioration, particularly the lack of use of tools (e.g. NEWS2) and equipment (e.g. pulse oximeters) to detect deterioration in primary and community settings
 - Decision-making processes not following the Mental Capacity Act.

Pauline Heslop, the University of Bristol's LeDeR Programme Lead, presented our analysis to the government's national [SAGE](#) committee (Scientific Advisory Group for Emergencies) on

13th November. Pauline said of her experience at SAGE 'The committee meeting spent an hour discussing the impact of COVID-19 on people with learning disabilities. I'm really pleased that LeDeR is being recognised nationally and taken note of.'

2. NHS England/Improvement's response to our report is available [here](#). This report identifies the actions that are being taken nationally to identify deterioration; strengthen decision-making; avoid diagnostic over-shadowing; and improve the provision of reasonable adjustments.

3. Public Health England have published a wider [analysis](#) of COVID-19 deaths of people identified as having a learning disability. This report brings together LeDeR data with NHS England's [COVID-19 Patient Notification System \(CPNS\)](#), and the CQC's [statutory notifications of deaths of people receiving social care](#).

Finally, adults with Down's Syndrome are now included in the COVID-19 clinically extremely vulnerable group. They are advised to take further precautions on top of the tougher national measures being introduced in the current 2nd wave 'lockdown'. Further information is available [here](#).

[LeDeR child death reviews – reminder for LACs and Reviewers](#)

Please ensure, for any child death notifications, you liaise with your local CDOP lead and upload the complete/ final CDOP form into the supporting documents before submitting the case. The eCDOP form should be used by default.

[Update on new LeDeR web based platform](#)

SCW (South, Central and West Commissioning Support Unit) continue the work on the new web-based platform for the LeDeR programme. SCW have completed the Discovery phase of the project, and are now working through the alpha phase. This is where features and ideas from the discovery phase are being tested to confirm the technology that will be part of the new platform. This will include the key functionality that users have identified as important and they are seeking. The new platform will be live by June 2021.

SCW will provide regular updates on the development's progress throughout the coming year. In the meantime if you have any queries or enquiries please contact jim.atkinson@nhs.net.



[Introducing the LeDeR team at NHS England](#)

We would like to introduce some of the wider LeDeR team to colleagues. We begin with Poppy Jhakra, poppy.jhakra@nhs.net a Learning Disability Officer at NHS England.

Poppy works alongside Lived Experience Advisers in the Learning Disability & Autism National Programme. Poppy works in the Health Improvement Team on various projects, with one being LeDeR. She helps to facilitate the work of the Health Improvement Team to make sure that the voice of people with lived experience informs all areas of work.

Poppy also supports advisers to make sure reasonable adjustments are made so that the right people are involved, in the right work, at the right time, and in the right way. This helps the projects to be inclusive, and ensures that what gets delivered is done by people, for people, to help them live healthier, happier, longer lives.

Next month, we introduce Ted Goodman, Family Carer Advisor at NHS England.

[New paper published about the LeDeR programme](#)

A new paper has been published in the Journal of Intellectual Disabilities called 'Establishing a national mortality review programme for people with intellectual disabilities: The experience in England'. You can access a copy of the paper [here](#).

[Physical activity and people with learning disabilities: lecture](#)

A lecture by Dr Thessa Hilgenkamp, Assistant Professor, Physical Therapy Department at the University of Nevada is available on [YouTube](#).

The lecture 'Physical activity and fitness for people with learning disabilities: from what we know to what we can do' was recommended to us by Ingrid Wilkinson Hart (@iaw07), Lead Physiotherapist, Community Team for People with Learning Disabilities at Wiltshire Health and Care.

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The next LeDeR monthly bulletin will be sent out in the middle of December 2020. Please email leder-team@bristol.ac.uk with any information to include by 9 December 2020.

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