

Learning Disabilities Mortality Review (LeDeR) programme

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LeDeR and intellectual disabilities research

The LeDeR team discuss the findings from the LeDeR reviews of deaths from sudden unexpected death in epilepsy (SUDEP) in a forthcoming issue of Epilepsy Professional magazine.

Our 2020 annual report found that epilepsy is the second most frequently reported potentially treatable cause of death in people with learning disabilities.

The forthcoming paper aims to redress the under-representation of people with intellectual disabilities in epilepsy research. We have found:

- missed opportunities to improve epilepsy related care, particularly in relation to medication
- a need to return to basic safety measures such as up-to-date care plans and assessments, and access to an epilepsy nurse between appointments.

The paper will be available from [Epilepsy](#) Professional or from leder-team@bristol.ac.uk.

Other research:

- a recent report by the Trisomy 21 Research Society about the findings of an international survey of COVID-19 and people with Down's Syndrome. See: https://www.t21rs.org/wp-content/uploads/2020/08/T21RS_COVID19_survey_august2020.pdf
 - and a new paper has been published about gender and the premature deaths of people with intellectual disabilities. See: <https://onlinelibrary.wiley.com/doi/10.1111/jppi.12360>
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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.

Every death is a LeDeR death

The LeDeR programme is a world-first. It is the first national programme aimed at making improvements to the lives of people with learning disabilities. Reviews of deaths are being carried out with a view to improve the standard and quality of care for people with learning disabilities.

Every death reported to LeDeR helps improve the care and quality of life of people with learning disabilities. And so it's vital that every death is reported to the programme – no matter if a life is rich and fulfilling and the death not unexpected. Every death is a LeDeR death.

Get this LeDeR bulletin sent directly to your inbox

If you've been forwarded this bulletin by a colleague, or friend, and want to have LeDeR bulletins sent direct to your inbox, you can add your name to our database by [emailing](#) the LeDeR team at the University of Bristol.

The next LeDeR monthly bulletin will be sent out around 23rd September 2020. Please email leder-team@bristol.ac.uk with any information to include by 9 September 2020.

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