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LeDeR

Learning from Lives and Deaths of People with a Learning Disability and Autistic People

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Why?

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- People with a learning disability have poorer physical and mental health outcomes than other people
- Men with learning disabilities die 23 years earlier than men without learning disabilities
- Women die 27 years earlier – preventable / health needs overlooked
- CIPOLD enquiry 2013

Key Points

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What is the Learning from Lives and Deaths – People with a Learning Disability and Autistic People (LeDeR) programme?

The aim of LeDeR is to drive improvement in the quality of health and social care services delivery and to help reduce premature mortality and health inequalities for people with a learning disability. As of late 2021, the programme includes improving services for people with autism.

Whose deaths should the LeDeR team be told about?

All deaths of people with a learning disability over the age of 4 years and the deaths of autistic people should be notified on the LeDeR website.

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Whose deaths will be reviewed?

All deaths will be reviewed, regardless of whether the death was expected or not, the cause of death or the place of death. Children and young people's deaths between the ages of 4 and 18 are reviewed as part of the child death review programme and the data is shared with LeDeR.

What is the process of reviewing deaths?

All deaths will receive an 'initial' review. If any concern or further learning is identified, or if the person is autistic or from a Black, Asian or Minority Ethnic background, a more detailed 'focused' review will be held.

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How does LeDeR fit with existing local and national reviews of deaths?

There are a number of different review processes (e.g., child death review, safeguarding adults review, review of deaths of people in hospitals) that might be required for any one death. In such cases the agencies involved will work together to do a LeDeR review to try to avoid unnecessary duplication. Reviewers will make it clear to family members where and how the LeDeR process links with other reviews, or investigation processes.

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What happens to the information collected from LeDeR reviews?

Once a review has been completed, the review report is partly anonymised. The partly anonymised review report is presented to the relevant ICS governance group whose role is to agree and take forward necessary changes to service provision, based on the findings of the review of death.

Each year NHS England analyses the information from all of the reviews and produces the annual LeDeR report.

Local Perspective

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- Barnsley CCG responsible for delivery of LeDeR locally
- 86 deaths notified between 2016 and 2022
- Action from learning is a key deliverable
- South Yorkshire ICS will be responsible for future delivery of LeDeR and there is an action plan in place
- Barnsley involved in delivery of LeDeR training to health and social care professionals via the ECHO programme

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https://leder.nhs.uk/

Oliver McGowan

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- LD and Autism
- Died at 18 years old in 2016
- Independent investigation report 2020 -death said to have been avoidable and LeDeR review process criticised
- Tireless campaigning by family highlighted the need for better training for health and social care professionals

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So What?

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- All health and social care professionals to have mandatory training appropriate to level of practice
- LeDeR policy and process revised

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thank you

Any Questions?

References

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