NHS
Herefordshire and Worcestershire
Clinical Commissioning Group

Learning from lives and deaths (LeDeR)Programme update- including autistic people

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Learning from the lives and deaths of people with a learning disability and autistic people (LeDeR) update

History of LeDeR

- Programme in place since 2017. Has to date focused on people with a learning disability.
- Programme aim is to improve services (and outcomes for people) by learning about what works and what things influence poorer health
- Person's death notified to LeDeR programme through a web based reporting system
- Retrospective review of how a person's health and wellbeing was managed
- Recommendations are made to reflect gaps that require improvement or areas of good practice that need to be more widespread

Change in scope of LeDeR to include autistic people

- Change in scope introduced in national LeDeR policy published in March 2021
- From February 2022 the LeDeR reporting system will be able to accept a notification for an autistic person to trigger a LeDeR Review. The person who died must be 18 years of age or over and have a diagnosis of autism that is confirmed within a clinical record.

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Next steps

- LeDeR Reviewers undertake additional training to help raise awareness of health needs associated with the lives of autistic people
- Raise awareness amongst those who are most likely to make notifications
- Ensure autistic people are part of the decision making to agree Review recommendations (LeDeR Learning into Action Panel)

How will LeDeR lead to improvement in health for autistic people?

- LeDeR Reviews make recommendations for service improvement
- Key recommendation themes will form part of the LeDeR Strategy 3 Year delivery plan (2022-2025)
- The Delivery plan in year one will aim to understand what influences the health of autistic people. The plan will be reviewed annually to incorporate new learning
- Existing LeDeR Priority workstreams will reviewed to reflects the needs of autistic people
- Progress with meeting the LeDeR delivery plan will be reported to the Tackling Health Inequalities Board

LeDeR Strategy- Key priority areas

1.Annual Health Checks and Health Action Plan completion, to inform robust reviews of a person's health needs and support meaningful plans to work toward sustaining or improving health outcomes.

2.Achieving the best life chances for those at risk of dying from r**espiratory illness.**

3.Supporting people's **emotional and mental health needs**.

4.Supporting people to make decisions about their care and improving their experience if they have a **life limiting illness or are nearing their last months or days of life.**

5.Zero tolerance to **avoidable deaths related to bowel impaction or bowel disease**

6.Ensuring that those living with **obesity** and their carers have accessible support to make informed choices about lifestyle factors that can improve their health.

7.Ensure carers, care staff and clinicians are skilled in enabling everyone to be supported to be part of **decision making about their health** and where this is not possible that Mental Capacity Act standards are followed, and Best Interest decisions are made and communicated

8.Enabling our ICS **workforce** to be equipped to recognise the essential needs of people with a learning disability, autistic people and their carers, so that they can provide effective care that achieves positive outcomes.

In addition to themes arising from Reviews there are other priorities that are important for us to improve:

9.Ensuring that we are **sharing information about what we are learning** and how we are working together to make improvements. We want to do more to give recognition and thanks where areas of good practice are identified within Reviews and to share examples of good practice with others as another way of supporting improvement.

10.Ensuring that the **notifications that we receive are representative of our local communities.** We need to make sure that we are doing all that we can to learn from every opportunity available to us. This includes people from ethnic minority backgrounds, autistic people, people who live in very rural areas.

11.Meeting the standards of the national LeDeR Policy. This includes having a dedicated workforce to undertake reviews in a timely way and making sure that our systems of reporting and monitoring helps us know if we are doing what we set out to achieve. It also includes ensuring that we continue to enable experts by lived experience (people with a learning disability and their family or paid carers) to be a key part of the LeDeR Programme locally. **During 2021/2022 this will expand to include Autistic people.**

How to tell LeDeR about the death of an adult diagnosed with autism

Anyone can notify LeDeR of a death

- A death can be notified by completing an online form within this link

Report the death of someone with a learning disability (leder.nhs.uk)

- For help with completing the form a telephone helpline can be accessed **01278 727411 (**Monday to Friday, 8.30am to 4.30pm - except public holidays)