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**Learning from lives and Deaths - People with a learning disability and autistic people (LeDeR) Programme**

**What is LeDeR?**

LeDeR is a service improvement programme for people with a learning disability and autistic people.

Established in 2017 and funded by NHS England and NHS Improvement, LeDeR works to:

* improve care for people with a learning disability and autistic people
* reduce health inequalities for people with a learning disability and autistic people
* prevent people with a learning disability and autistic people from early deaths

**How do we do this?**

We will review information provided to us by families, close carers, GPs and other professionals about the health, care and support each individual received. We will then identify and share good practice plus practice that could be improved on.

A LeDeR review is not an investigation or part of a complaints process. It looks at key episodes of health and social care the person received that may have been relevant to their overall health outcomes. It is not just restricted to the last episode of care before the person’s death.

Reviews will be completed as soon as possible so that where good practice or concerns are identified, these can be shared and addressed quickly.

**Why do we need LeDeR?**

In 2013 there was a Government Enquiry called CIPOLD (Confidential Inquiry into premature deaths of people with learning disabilities). It found, amongst other things, that people with a learning disability were dying more than 20 years earlier than people without a learning disability from illnesses that were treatable. This was often due to delays in diagnosis and treatment or lack of reasonable adjustments.

Current research states that autistic people who do not have a learning disability are dying 16 years earlier than people who do not have autism.

**What happens in a LeDeR review - How to be involved in a LeDeR review**

The LeDeR Programme reviews the deaths of all people with learning disabilities (notified to us) and all autistic people aged 18 and over. Deaths can be notified to LeDeR on the website [LeDeR - Home](https://leder.nhs.uk/). Notifications can be made by anyone including family members or friends of the individual or by any professional that has worked with them. It doesn't matter if we are notified about the same person more than once.

* A review is allocated to a reviewer in the area that the person died. An Initial review then takes place. The reviewer contacts the person's family, a friend or a carer who they were particularly close to. They can choose whether to share their thoughts about the care and support received by the individual as well as more person-centred information like what was important to them and how they communicated their likes and dislikes.
* The reviewer will also contact the GP and one other person who worked with the person or knew them well.
* After this, the reviewer uses their judgement to decide if a focused review needs to happen. A focused review will usually happen if:
  + the reviewer finds areas of concern or things they think we can learn from
  + the person is from a Black, Asian or minority ethnic background
  + the person was autistic with no learning disability
  + the person had been under mental health or criminal justice restrictions at the time of death or 5 years previously
* A family member can always ask us to complete a focused review. A conversation can take place between the family and the reviewer or LAC about the expected outcome of a LeDeR review.
* A focused review will look in more detail at the person’s life. The review will also involve more people with different jobs.

**How contributing to a LeDeR Review can help other people with learning disabilities or autism in the future**

By looking at key periods of a person's life as well as the circumstances leading up to their death and finding out from families what, if anything, could have been done differently, we will have a better understanding about the service improvements that need to be made as well as the good practices that need to be shared more widely across the country.

The completed focused review will go to the local governance group or panel with the areas of learning, good practice and concern. The group or panel will decide on actions to take, who will take these actions and the help they need to reduce health inequalities and stop people dying too young.

Learning and recommendations from every review (initial and focused) are recorded by the Derbyshire LeDeR Team and themes are shared and discussed with Commissioners and Provider agencies at the Derbyshire LeDeR Steering Group. This supports service changes across Derby and Derbyshire. Information is also collected and reported on locally and nationally by NHS England and NHS Improvement in the national LeDeR Annual Reports. This informs NHS forward planning as part of the NHS Long Term Plan [NHS Long Term Plan](https://www.longtermplan.nhs.uk/).

Further information and resources about learning disability and autism are available on the [Joined Up Care Derbyshire website](https://joinedupcarederbyshire.co.uk/your-services/learning-disabilities-and-autism/)

Or for more information about LeDeR in Derbyshire, contact Lisa Coppinger (Local Area Contact for LeDeR) at [lisa.coppinger@nhs.net](mailto:lisa.coppinger@nhs.net)