



LEARNING DISABILITY, AUTISM & SAFER HEALTHCARE

LeDeR

Learning from Lives and Deaths

Understanding reviews, learning from care and improving services for people in England.

The key idea

LeDeR reviews look at the health and social care received by adults with a learning disability and autistic adults whose deaths are notified to the programme. The purpose is to identify learning, improve local services, reduce health inequalities and help prevent avoidable early deaths.

What is LeDeR?

LeDeR stands for Learning from Lives and Deaths - people with a learning disability and autistic people. It is an NHS England service-improvement programme. Integrated care systems review the health and social care received by adults aged 18 and over with a learning disability and autistic adults whose deaths are notified to LeDeR.

In everyday language

A LeDeR review looks back at important parts of a person's health and social care to understand what worked well, what could have been better and what services can learn for the future.

Why does LeDeR matter?

People with a learning disability and autistic people experience significant health inequalities and barriers to care. LeDeR is intended to help local and national systems understand why people are dying early and identify changes that could improve care and reduce inequalities.

What does a review look at?

A LeDeR review is broader than simply examining the final hospital admission or last episode of care. It can consider key episodes of health and social care that may have affected the person's overall health outcomes, while also taking account of other mortality reviews that have occurred.

Key distinction

A LeDeR review is not itself a mortality investigation, a complaints process, a safeguarding enquiry or a coroner's investigation. Those processes can exist separately. Serious concerns about care may need to be raised through the appropriate route as well.

Who can notify a death?

Anyone can notify an eligible death through the online LeDeR system. This can include health or care staff, family members, colleagues and other people who knew the person. NHS England states that every notified eligible death receives an initial review.

Initial review

The initial review gathers and considers information about the person's health and social care. The reviewer uses professional judgement and the available evidence to decide whether a more detailed focused review is required.

Focused review

A focused review explores relevant areas in greater depth. NHS England states that a focused review will always be completed for a notified autistic person and for a person from an ethnic minority background. A family also has the right to request a focused review.

Important to know

Not every LeDeR review follows exactly the same pathway. The amount of detail needed depends on the circumstances, evidence available and whether the criteria for a focused review are met.

Families and people who knew the person

Families and others who knew the person may hold information that records alone cannot show: how the person usually communicated, changes from their normal presentation, what support helped, previous experiences of services and concerns they raised. Their perspective can therefore be important to understanding the person's care.

What this might look like

A record may say that a person was 'quiet' during an appointment. Someone who knew them well might explain that becoming unusually quiet was one of their clearest signs of severe pain. That context can change how an episode of care is understood.

Learning from reviews

Reviewers identify good practice as well as areas where care or services could improve. Findings are considered through local LeDeR governance arrangements. Integrated care boards are responsible for using learning from reviews to change services and must publish annual information about action taken, alongside a three-year action plan.

From an individual review to service improvement

LeDeR is designed to do more than describe what happened to one person. When similar issues appear across reviews, local and national analysis can reveal patterns that services need to address. NHS England also commissions analysis of LeDeR data to support national learning.

Important principle

The value of a review depends on learning being translated into action. Identifying a problem is only the first step; services need clear, measurable changes and a way to check whether those changes have improved care.

Diagnostic overshadowing

Diagnostic overshadowing happens when physical or mental health symptoms are wrongly attributed to a person's learning disability or autism instead of being properly assessed. LeDeR learning has contributed to wider attention to this risk within safer healthcare.

Example

A new change in behaviour should not automatically be described as part of a person's learning disability or autism. Pain, infection, constipation, medication effects, mental health difficulties and other causes may need assessment.

Communication and reasonable adjustments

Communication barriers and inaccessible care can affect whether symptoms are understood and whether a person can participate in decisions. Reasonable adjustments might include accessible information, extra processing time, quieter environments, different appointment arrangements, communication aids or involvement of someone who understands the person's communication.

Recognising deterioration and changes from baseline

A person's usual presentation - sometimes called their baseline - can provide important clinical context. Family, carers and support staff may notice subtle changes in eating, movement, sleep, communication, behaviour or alertness. These observations should be considered alongside clinical assessment rather than dismissed.

Important clinical point

A person may communicate illness or pain differently from what clinicians expect. Outward appearance, speech or behaviour should not be used on their own to judge how unwell someone is.

What LeDeR cannot replace

LeDeR should not be relied upon instead of immediate patient-safety action. If there is a current safeguarding concern, serious concern about care, complaint, patient-safety incident or question requiring a coroner, those issues need the appropriate process. A later LeDeR review does not replace action that should happen now.

For families and supporters

If you are contributing to a review, it can help to describe the person as an individual rather than focusing only on diagnoses. Information about their usual health, communication, daily life, previous care, reasonable adjustments and changes noticed before their death may all provide useful context.

Practical check

What was the person's usual presentation? Were changes recognised? Were symptoms investigated? Were communication needs and reasonable adjustments addressed? Was information from people who knew the person considered? What learning needs to result in a concrete change?

References & Further Resources

This guide describes the LeDeR programme in England. Programme processes can be updated, so current NHS England information should be used when notifying a death or checking review arrangements.

NHS England - LeDeR	The main NHS England overview explains the purpose of LeDeR, who receives an initial review, when focused reviews are used and how a death can be notified.
NHS England - Who is involved?	Explains the responsibilities of NHS England, integrated care boards and local LeDeR governance groups, including service-improvement actions and local reporting.
LeDeR annual reports	Annual analysis brings together findings from completed reviews to identify patterns in mortality, health inequalities, quality of care and areas requiring improvement.
Action from learning reports	These reports give examples of how integrated care boards and local systems have changed services in response to learning from LeDeR reviews.
LeDeR online notification system	Anyone can notify an eligible death. The current NHS England LeDeR page links to the online reporting route and should be used for up-to-date instructions.

How to use these resources

Use NHS England's current LeDeR pages for the review process and notification route. Annual reports are useful for understanding broader patterns, while Action from Learning reports show how review findings can be translated into changes in services. A LeDeR review is not a substitute for complaints, safeguarding, patient-safety or coronial processes where those are required.