# LeDeR 2021

## Learning from Lives and Deaths – People with a Learning Disability and Autistic People


NHS England and NHS Improvement

# About this document

Blue word glossary

## Blue words:

**When a word or phrase is difficult, it is in blue writing. The word is then explained.**


**This is the easy read summary of the LeDeR policy 2021.**


**You can view the full document of the LeDeR Policy 2021 on this website:**

**http://bit.ly/NHS-LeDeR**


**This document is quite long. We have split it up into different sections to make it easier to read.**

**You may want to read it in sections.**

# What's in this document?

# What's in this document?

# 1. About LeDeR


**LeDeR is about learning from the lives and deaths of people with a learning disability and autistic people**


**We are making some changes to how LeDeR works.**


**This is a new policy that explains how we will learn from people's lives and deaths and how we will make things better.**

# 1. About LeDeR

**LeDeR used to stand for the Learning from Deaths Review programme.**


**Now we have changed the name to learning from lives and deaths – people with a learning disability and autistic people.**

**For the first time LeDeR will review the lives and deaths of autistic adults who do not have a learning disability.**


**When we say people in this document we mean people with a learning disability and autistic people.**

# 1. About LeDeR


**The LeDeR programme aims to -**

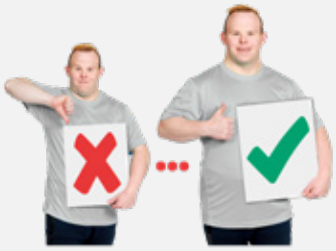

1 **Improve health and social care for people with a learning disability and autistic people.**


2 **Reduce health inequalities for people with a learning disability and autistic people.**

**Health inequalities are unfair and preventable differences in health.**

3 **Stop more people from dying too soon by making care better.**

# 1. About LeDeR



**LeDeR helps us know how to make services better.**


**LeDeR tells us the main reasons people die too soon.**

**People with a learning disability, autistic people and their families are involved in all the work LeDeR does.**

**A LeDeR review will look at a person's life as well as how they died.**

# 1. About LeDeR

This helps us find out where care has been good and where care could have been better.


We do a review as quickly as we can after someone has died.


In the future reviewers will have a job in a team to do LeDeR reviews.


There are lots of different ways we find out about someone's life and death.

These can be called reviews too.

# 1. About LeDeR


One example is a safeguarding review.

This looks at how a person was protected from abuse or neglect.

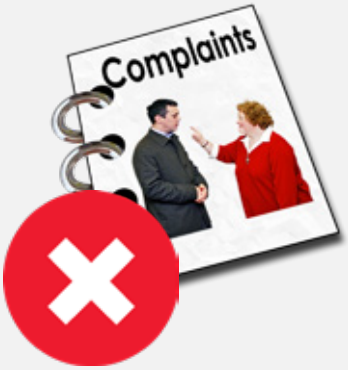
Another example is a coroner's review which is when a type of judge looks closely at the person's death.


A Child Death Review is done for all children who die aged 4 and over.


The report from the Child Death Review is then given to LeDeR.

# 1. About LeDeR


**LeDeR works together with other types of reviews to make sure we have a lot of information about a person's life and death.**




**A LeDeR review is not the same as a review that happens after someone has made a complaint.**

**If you are worried about the care that someone got before they died you can make a complaint. You will not get into trouble for making a complaint.**

# 1. About LeDeR

**You can report what you are worried about to -**

1 **The care provider, this might be a hospital or social care provider.**


2 **Care Quality Commission (CQC)**
**They makes sure health and social care services provide people with the best care possible.**

**http://bit.ly/CQC-Report-Concerns**

# 2. Who has a LeDeR review

**The people who will get a LeDeR review are -**

**People with a learning disability and autistic adults.**


**By autistic adults we mean people over the age of 18 who have been told by a doctor they are autistic and had this written in their medical records.**

# 3. Why LeDeR is changing


**In the past the University of Bristol were involved in running LeDeR.**


**The contract with the University of Bristol will end in May 2021.**


**Since LeDeR started we have done almost 9000 reviews.**


**We thought it was a good time to look at what has gone well with LeDeR and what needs to be better.**

# 4. When the changes will happen


**The new way of doing reviews will begin on 1 June.**


**Reviews for autistic people will start later in 2021.**

# 5. About the new policy


**We have written a new policy to make sure LeDeR makes a difference in the future.**


**To write the policy we worked with -**

**People with a learning disability**

**Families of people with a learning disability who have died**

**Other Families and carers**

**Health and social care professionals**

**Self-advocacy groups**

# 5. About the new policy

**We also looked at information from the review into Oliver McGowan's death.**


**You can find out more about that review here:**

**http://bit.ly/LeDeROliverMcGowan**


**The new policy will help anybody in health or social care who has anything to do with LeDeR.**

**This includes -**

**NHS staff**

**Social care staff**

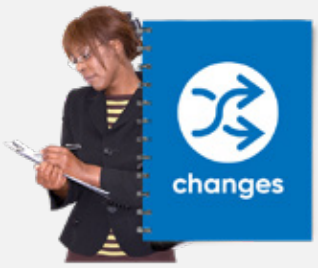
**Council staff**

**Voluntary organisations**

# 6. Who is in charge of reviews


In the past it has been clinical commissioning groups who made sure a LeDeR review was done.


A clinical commissioning group, sometimes called a CCG is an NHS organisation that plans and pays for services in your local area.




The CCG was in charge of making sure changes were made after reviews were done.

In the future integrated care systems will make sure reviews are done and changes are made.

# 6. Who is in charge of reviews


An integrated care system, sometimes called an ICS, brings together NHS, council, community and voluntary organisations to support people in their area.


You can find more information on ICSs:

https://www.youtube.com/watch?v=3YdlV1DsK54

# 7. Telling us about a death


**Anyone can tell LeDeR that a person has died. They will do this through a new website.**

**We want to know about as many deaths as possible so we can learn from them.**

# 8. Supporting reviewers to do a good job


**We are changing how the people who do reviews are trained.**

**This will help make sure that all reviews are done well.**

**Reviewers will work in bigger teams.**

**Reviewers can ask their team to help them with a review if they need to.**

# 8. Supporting reviewers to do a good job

**Reviewers will have more people to help them find the information they need.**

# 9. Working with families

**Families will still be involved in a LeDeR review if they want to be.**

**They can be involved in these ways -**

1 **They can be told about the review.**

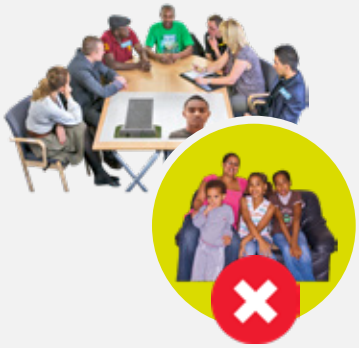
2 **They can talk to the reviewer about the person who has died.**


3 **They can comment on a draft review and see the final review.**

# 9. Working with families


4 They can be given information about bereavement support.

Families can choose how much they want to be involved.



A review will still happen even if the family does not want to be involved.

# 10. What happens during a review

First, the reviewer will do an initial review.

This is when the reviewer talks to -

- People who knew them well.

  For example their family.


- The person's doctor (GP).

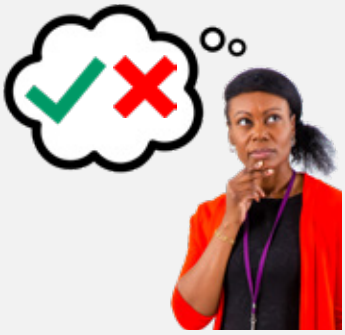
  If they can't talk to the doctor, they will look at the person's GP records.

# 10. What happens during a review

- **At least one other person who knew them.**

**There are two different types of LeDeR review.**

**Everyone has an initial review and some people also have a focused review.**



**After the initial review, the reviewer will decide whether a focused review is needed.**

**A focused review will look at some parts of a person's care in more detail.**

# 10. What happens during a review

There are some times when a focused review will always happen.

These include -

- Anyone is worried about the care that the person got.

- If the person was an autistic adult who did not have a learning disability.

- If the person was from a Black, Asian or Minority Ethnic background.

# 10. What happens during a review

- **If the reviewer decides that there is a lot to learn from doing a focused review.**

**Families can talk with a reviewer if they think a focused review is needed.**

**The reviewer may decide there are other ways to look at the person's death.**

**Everyone looking at a person's death should work together to make sure that families don't have to answer too many questions.**

# 11. What happens after a review


Once a review is finished the reviewer will tell the integrated care system what they have learned.


An integrated care system, sometimes called an ICS, brings together NHS, council, community and voluntary organisations to support people in their area.

A group of people from the ICS will check that reviews are good.


They will also say what needs to be done to make things better.

These are sometimes called actions.

# 11. What happens after a review

**The group from the ICS will include -**

- **People with a learning disability**

- **Autistic adults**

- **Family and carers**

# 11. What happens after a review

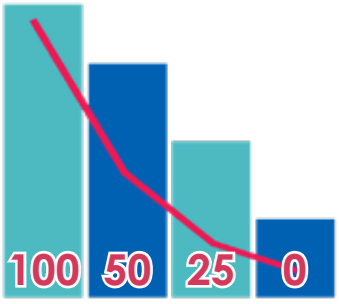

- **People who work for health and social care organisations in the area.**


**We will make sure that ICSs use what they have learned from LeDeR reviews to make care better.**

# 12. Checking that LeDeR is working


**We will know LeDeR is working when -**

- **Fewer people are dying from things which could have been avoided.**



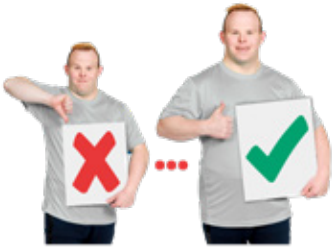

- **We stop seeing the same issues coming up in reviews over and over again.**

  **These might be things like -**

- **Families not being listened to**

# 12. Checking that LeDeR is working

- **People not getting the right medicine when they leave hospital.**



- **We can see that services are getting better because of what they have learned in reviews.**

# 13. Using personal information

Organisations are not normally allowed to share personal information about people.

LeDeR has been given special permission to be able to look at information about people with a learning disability who have died.

We are asking for permission to look at information about autistic adults who have died.

This is so that we can make care better and stop people dying too soon.


This special permission is called Confidentiality Advisory Group (CAG) Section 251 approval:

http://bit.ly/ConfidentialityAdvisoryGroup

# 13. Using personal information


**LeDeR still needs to follow these rules on keeping information private -**


- **General Data Protection Regulation (GDPR)**

  **A set of rules for collecting and using personal information from people.**


- **Common law duty of confidentiality**

  **This means people's health information must not normally be revealed without their consent.**


- **Data Protection Act 2018**

  **A law that controls how your personal information is used by organisations, businesses or the government.**

# 13. Using personal information


- **The Data Security and Protection Toolkit (DSP Toolkit)**

  **A toolkit to make sure NHS patient data is used properly.**


- **National Data Opt Out**

  **A set of rules for collecting and using personal information from people:**

  **www.nhs.uk/your-nhs-data-matters/**


**Some more information about personal information is here:**

**http://bit.ly/GDPR-EasyRead**

# This document was made in co-production with:

Experts by experience: **people with a learning disability** and **autistic people**

**Ace Anglia:** info@aceanglia.com
**NHS England and NHS Improvement**