1 Learning disabilities mortality review (LeDeR) - background

People with a learning disability / autism often have poorer physical and mental health than others, and may face barriers to accessing health and care to keep them healthy.

Too many people with a learning disability and autism are dying earlier than they should, many from things which could have been treated or prevented.

The learning from deaths of people with a learning disability and autistic people (LeDeR) programme is a service improvement programme to look at why people are dying, and what we can do to change services locally and nationally to improve people's health, and reduce health inequalities.

2 LeDeR annual reports

The Humber and North Yorkshire Health and Care Partnership have recently published the *Learning from lives and deaths - people with a learning disability and autistic people* annual report, which can be accessed here.

The *National learning from lives and deaths - people with a learning disability and autistic people* annual report can be accessed here.

3 LeDeR new policy

In 2021, NHS England published their first LeDeR policy which sets out the core aims and values, and expectations of different parts of the health and social care system in delivering the programme.

This policy was written with the help from:

- People with a learning disability / autism.
- Families of people with a learning disability / autism who have died.
- Other family, carers.
- Health and social care professionals.
- Self - advocacy groups.

4 Who is involved in LeDeR?

NHS England manages the programme and ensures LeDeR reviews are completed, and local improvements are made.

Integrated Care Boards are responsible for ensuring LeDeR reviews are carried out for deaths in their area.

LeDeR steering groups ensure that the learning from completed reviews improve the care and treatment of people with a learning disability / autism in their area.

People with lived experience, family and carers help to develop local services, and are a very important part of the ongoing delivery of the LeDeR programme.

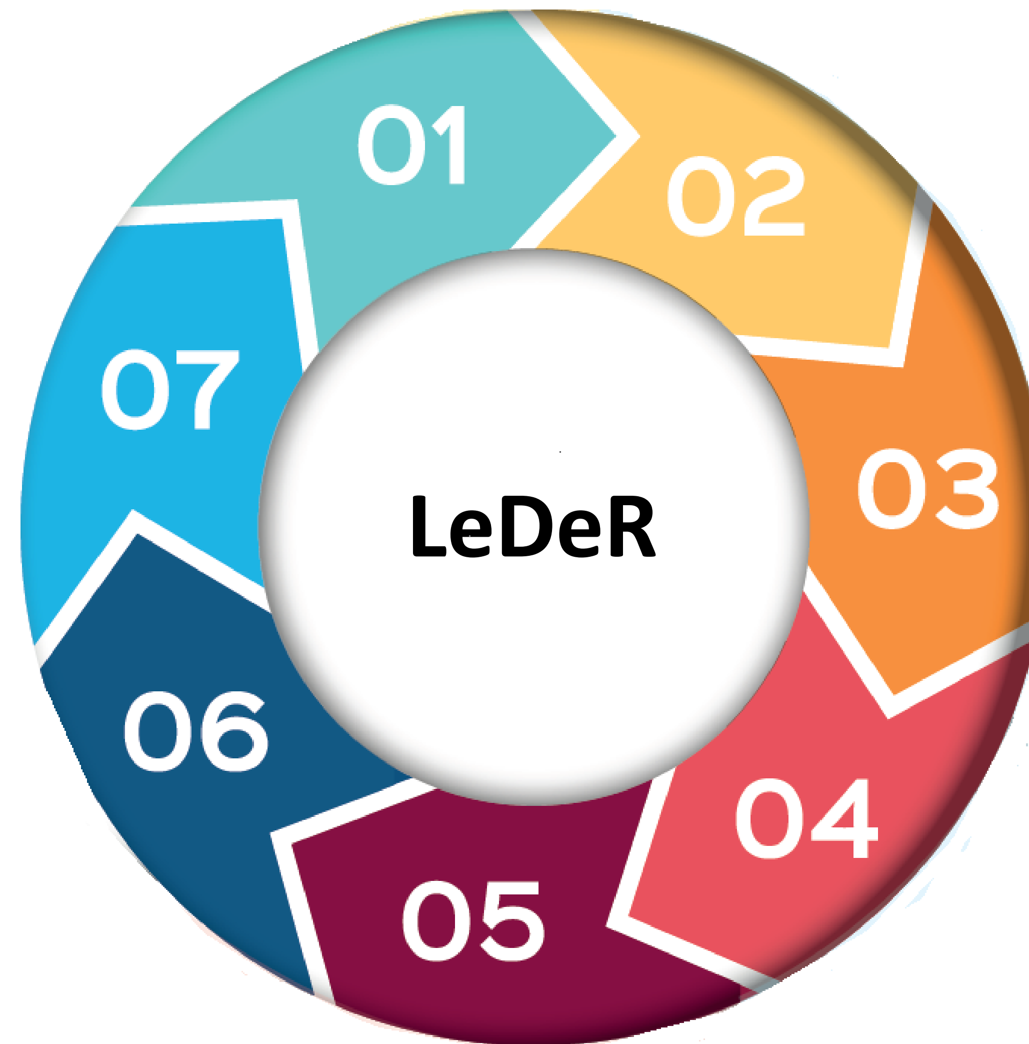
GPs, hospital trusts, social care providers, and other professionals can support people to live happy and healthy lives through things like annual health checks and making reasonable adjustments.

5 Why it matters

A reviewer looks at the person's life and the circumstances that led up to their death.

This involves gathering information from GPs records, social care / hospital records, and by speaking to family members and care staff about the person who has died.

Once the information is reviewed, recommendations are made about what improvements are required locally, to services for people with a learning disability.



6 Key outcomes and learning

Findings from LeDeR reviews are used to make changes to services locally.

It is known already that more work needs to be done in areas of respiratory conditions, epilepsy, sepsis, constipation, cancer, Do Not Attempt Cardiopulmonary Resuscitation (DNACPR), and deaths of people from BAME communities.

For more information, please visit NHS actions from learning.

7 Further information

For information relating to safeguarding adults, please visit www.northlincssab.co.uk.

For more information about LeDeR, please visit the NHS website.

To report a death of someone with a learning disability or an autistic person, please visit Report the death of someone with a learning disability (leder.nhs.uk).

For the updated LeDeR policy, please visit NHS England » Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy 2021.

7 Minute Briefing