Action From Learning
LeDeR Report
2021 – 2022
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What is LeDeR?

When a person with a learning disability dies, a LeDeR review looks at the health and social care the person received.

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

From early in 2022 LeDeR reviews began to look at the deaths of autistic people.
What is LeDeR?

This document is the Action from Learning easy read report which explains what we have learned from all the LeDeR reviews.

Action from learning means learning from LeDeR reviews to make the right changes so that people live longer and healthier lives.
We want to say ‘thank you’ to

• Families and health and care workers who have taken part in a LeDeR review

• Families who have shared their memories and experiences in this report

• Health and care workers who have made the lives of people with a learning disability and autistic people better in the last year.
First thoughts

Every death of a person with a learning disability or an autistic person is sad.

This report will tell you about the good changes we have made because of what we have learned.

So that people can live happier and healthier lives.
First thoughts

In this section you can read what three people who work for **NHS England** think about **LeDeR**.

**Tom’s thoughts**

Tom Cahill is the National Director for Learning Disability and Autism.

“People with a learning disability and autistic people are still dying too young.”
First thoughts

“LeDeR reviews show us what needs to change.”

“I will work to make sure health services learn from LeDeR reviews and do things better.”

“This report shows how working together can lead to people with a learning disability and autistic people living better and healthier lives.”
“It is important that people are more involved in their care.”

Dr Roger Banks is the National Clinical Director for Learning Disability and Autism.

“We know that coronavirus has had a big effect on people.”
First thoughts

“This makes the **NHS** want to do much more to make care better.”

“This year we have started to look more closely at the lives and deaths of people from **minority ethnic groups**.”

“**Minority ethnic groups** means people who are not White British.”
“The **NHS** is making sure that reasonable adjustments are made for everyone who needs them.”

“**Reasonable adjustments** means making it easier for disabled people to use the **NHS**.”
First thoughts

Carl’s thoughts

Carl Shaw is a Learning Disability and Autism Adviser

“I work as a learning disability and autism adviser for NHS England.”

“I think it is really important that LeDeR reviews are now being done for autistic people.”
First thoughts

“Over the next year I would like healthcare professionals to learn more about the different needs of:

- people with a learning disability
- autistic people.”
Andrew’s story

A new video has been produced in the North East of England after a LeDeR review.

Go to YouTube and search for See Me Andrew’s Story

The video tells health and social care staff and everyone else to:

• listen to people with a learning disability

• question their ideas about doing the right thing for people with a learning disability.
Andrew’s story

The video is about the experiences of Andrew who died in early 2020.

The film was produced by the local drama group MiXiT.

Andrew was 51 but was very frail and he lived with Down’s syndrome.
Andrew’s story

Andrew went into hospital with a very bad urine infection.

He was not getting better from the urine infection and staff did not find out why he was still ill.

Staff thought Andrew was acting differently because of his dementia and learning disability.
Andrew’s story

So staff did not work out that he had two broken hips.

County Durham Clinical Commissioning Group and County Durham and Darlington NHS Foundation Trust are sharing Andrew’s story to show that:

• reasonable adjustments should be made for people with a learning disability and autistic people

• no-one should assume how autistic people and people with a learning disability behave.
Andrew’s story

Andrew’s family agreed for the video to be made.

His family hope Andrew’s story will change how health and care staff think about people with a learning disability and autistic people.

The video was made to be Andrew’s voice because he could not speak when he was alive.
Andrew’s story

The video was made to help people understand how to:

- see the person, not their learning disability or autism
- ask the right questions
- look out for problems so they do not get missed.
Safe and wellbeing reviews

Extra checks were made last winter on people with a learning disability and autistic people in mental health hospitals.

The checks made sure:
- people were safe and well
- any safety concerns were sorted out in the right way.

The information found from the checks is being used to make services better for people with a learning disability and autistic people.
Every area in England will have a LeDeR champion.

The LeDeR champions in the areas across England will:
- check that the NHS is making care better for people with a learning disability and autistic people
- take action if they do not think services are getting better.

The LeDeR champions also have to tell us what they are doing to make care better for people from minority ethnic groups.
People with a learning disability are more at risk of becoming seriously unwell if they get coronavirus.

The NHS has found a lot of new ways to support vulnerable people with coronavirus.
In the last year the NHS:

- made sure that people with a learning disability could have coronavirus vaccines sooner than other people
- made lots of films and other types of information about coronavirus vaccines
- made sure that invitations for coronavirus vaccines were easy to understand
Coronavirus

- helped to make the coronavirus vaccine booking service easy to use

- helped to train staff so that everyone has a good experience when they go for their coronavirus vaccine

- worked with Misfits Theatre company to make a film about how important it is for people with a learning disability to get the vaccine.

Go to YouTube and search for ‘Misfits vaccine NHS’
• made sure that people who could not go to a vaccine centre could still get their vaccine:
  ○ at home
  ○ at a place better suited to their needs

• made sure that people who are at high risk of becoming seriously unwell from coronavirus could get new treatments.
Do Not Attempt Cardiopulmonary Resuscitation or DNACPR
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Breathing problems cause a lot of people with a learning disability to die too soon.

There is a health problem called dysphagia which lots of people with a learning disability have.

It means you find it difficult to swallow and can affect your breathing.

Food or other things can get in your lungs if you have problems swallowing and lead to an infection called aspiration pneumonia.
Breathing problems

A guide on pneumonia and aspiration pneumonia was written by the British Thoracic Society.

The British Thoracic Society is a team of:
- doctors
- nurses
- scientists.

The team worked with people with a learning disability and their families.
Breathing problems

The NHS is also writing information to help healthcare staff so they can:

- stop people getting pneumonia
- give people the right treatment.

Hospitals will get extra money for treating people with pneumonia properly.
Flu vaccines are still very important for people with a learning disability.

LeDeR reviews say people with a learning disability sometimes miss out on treatments such as flu vaccines which help to stop serious illness.
By February 2022 the flu vaccine had been given to 3 out of every 4 people with a learning disability who needed it.

Updated information about the vaccine.

Gave doctors (GPs) an easy read letter to invite people to get their vaccine.
Noticing when someone is becoming very unwell

LeDeR reviews have told us that:

• families and carers can tell when the person they care for is getting more unwell

• families and carers need to know how to quickly get the right help for the person they care for.
Noticing when someone is becoming very unwell

The NHS has worked with:

• The Royal College of Physicians

• The Society for Acute Medicine.

Both organisations are groups of doctors, nurses and scientists.
Noticing when someone is becoming very unwell

We asked both organisations to make a document for healthcare professionals who:

• work in hospitals

• give emergency care to people with a learning disability.

The Royal College of Physicians put this document out on 1 April 2022.
**Constipation**

*Constipation* is when you find it difficult to poo.

Some people with a learning disability are more likely to have problems with *constipation*.

People with a learning disability are often given *medicine* to treat constipation.
There is a project to tell people more about constipation.

The project will help people understand how to:

- treat constipation
- stop someone getting constipated
- find out if someone is constipated.
People with a learning disability are less likely to die of cancer.

But LeDeR reviews found out that it takes a long time for people with a learning disability to find out if they have cancer.

One of the reasons for this is that a lot of people with a learning disability do not get cancer screenings.
Cancer

What the NHS did in the last year:

- put out new information about cancer screening

This information explained how the NHS can make breast cancer services easier for everyone to use.

www.mencap.org.uk/advice-and-support/health-coronavirus/cancer-screening
Cancer

- asked doctors (GPs) who is on their learning disability register so that the cancer screening programme has this information

- looked at the invites and follow up letters from the NHS cancer screening services to make sure they are easy to understand

- gave doctors (GPs) new information to make sure autistic people and people with a learning disability have their cancer screening.
Cancer

- made sure that **NHS** information about cancer screening on the television and internet is:
  - easy to understand
  - includes people with a learning disability

- offered lung screening for some people who used to smoke to see if they might have lung cancer
• made sure that surveys about patient care are easy to understand

• worked with Prostate Cancer UK and checked their easy read information.
Epilepsy is a condition that affects the brain and causes seizures.

Seizures can change how a person:
- behaves
- moves
- feels.

Lots of people with a learning disability have seizures.
SUDEP Action are a charity that gives advice on how to stop people dying too young from epilepsy.

SUDEP Action has a safety checklist which you can watch as a video on their website sudep.org/checklist

The NHS gave money to SUDEP Action to make the checklist easier to understand.
The NHS has been working with NICE on **new guidelines** for finding and managing **epilepsy**.

**NICE** is short for the National Institute for Health and Care Excellence.

NICE find out what **works well** in health and social care and comes up with guidelines and advice.
Annual health checks

The NHS wants everyone with a learning disability who wants an annual health check to have one.

Annual health checks can find health issues before they become a big problem.
We know that lots of **good work** was done **across the country** because many more people had an **annual health check** last year.

We are making sure that people with a learning disability who are in **prison for longer than a year** can also get an **annual health check**.

**Image source:**
LeDeR tells us that people from minority ethnic groups with a learning disability die younger than white people.

We know that not everybody from minority ethnic groups is on their GP learning disability register.
The health of people from minority ethnic groups

We are working with other organisations to change this.

The NHS have employed someone to make sure more people from minority ethnic groups get the right care at the right time.
The health of people from minority ethnic groups

The **NHS** are working with three organisations to help us understand how to make **health care better** for people from **minority ethnic groups** with a learning disability.

The three organisations are:
- Learning Disability England
- The Race Equality Foundation
- and The NHS Race and Health Observatory.

This work looks at:
- how the **NHS** works with people, families and carers
- how local areas can support people to be treated fairly.
The health of people from minority ethnic groups

A report on this work will come out later in 2022.

The NHS Race and Health Observatory is finding out how people from minority ethnic groups get healthcare.

The NHS Race and Health Observatory carries out research to find out if minority ethnic groups get a different health and care service to everyone else.
Local areas are working to understand **how many** LeDeR reviews there should be about people from **different minority ethnic groups** in their **area**.

Local areas need to have a **plan** to **make sure** that people from minority ethnic groups get the **same level of care** as other people.
Cardiopulmonary resuscitation (CPR) is when someone tries to make a person’s heart start again if it stops.

DNACPR is short for Do Not Attempt Cardiopulmonary Resuscitation.

If people do not want to be resuscitated, they can choose to have a DNACPR.

This means a health professional will not try to start their heart again if it stops.
A **decision** about DNACPR is a personal choice and must only be made by talking to the **person**.

In some cases their **family or carers might be** involved in the decision.

The **NHS** is doing **more work** to make sure that **DNACPRs** are put in place correctly and matches the persons own choices.
Reasonable adjustments

Digital flag

The NHS wants more information about reasonable adjustments on the electronic records for people with a learning disability and autistic people.

This is called a digital flag and can help medical staff to:

- make sure services are easier to use
- make hospital visits a better experience.
Reasonable adjustments

Before all of the NHS starts using the new digital flag a group of organisations will try it out over the next year to see how well it works.
We asked Misfits Theatre Company to make a film about reasonable adjustments for healthcare professionals.

Go to www.youtube.com and search for ‘reasonable adjustments nhs’

https://www.youtube.com/watch?v=IQynWG4LCnw
Psychotropic medicine is medicine that can change your:

- thoughts, mood, feelings
- the way you behave.

This medicine is given for different reasons such as:

- mental health conditions
- sleep problems
- epilepsy.
People with a learning disability and autistic people are more likely to be given these medications.

Sometimes people are given medication to change their behaviour.

Sometimes people with a learning disability are given too much medication.

Sometimes people with a learning disability take the medication for a long time.
A big campaign called **STOMP-STAMP** is trying to make sure that people get:

- the right medication at the right time
- only when they need it.

The campaign is looking at **other ways** to **support** people who take **psychotropic medication**.
We have worked with the National Autistic Society to make STOMP information for autistic people and their families that explains:

- psychotropic medicine
- medication reviews.
LeDeR promise

In the next year the LeDeR team will:

1. Work with people who run:
   - cancer screening services
   - cancer treatment services

   to make these services better for people with a learning disability and autistic people
LeDeR promise

2. Check that DNACPR forms are being completed correctly

3. Support local services to use the new NHS information pack on breathing problems

so that care for people with a learning disability and autistic people will get better.
4. Find out why people with a learning disability and autistic people are more likely to:
   - get high blood pressure
   - have problems with their heart or blood vessels.

5. Find out if putting hospital passports on mobile phones or computers makes them easier to use.
6. Work with other organisations to train more carers and staff so they can quickly notice when a person with a learning disability or an autistic person becomes unwell.
7. Make an information pack about using CPAP machines for:

- people with a learning disability
- autistic people
- their carers.

A CPAP machine helps people to breathe while they are asleep.
8. Start a social media campaign to give these groups useful information on preventing and treating constipation:

- people with a learning disability
- autistic people
- carers
- health professionals.
Find out more

You can find out more about:

the **NHS England LeDeR programme** at [leder.nhs.uk/](https://leder.nhs.uk/)
