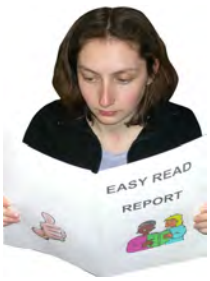
NHS
North Central London
Clinical Commissioning Group

LeDeR annual report 2020-2021



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What is in this report

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About this report

NHS
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This is the second LeDeR report of the North Central London Clinical Commissioning Group or NCL for short.

LeDeR stands for Learning Disabilities **Mortality Review**.

Mortality is when people die.

A **review** is looking back on what has happened.

LeDeR looks at all the deaths of people with learning disabilities.

This report is about:

- some changes to LeDeR
- all of the LeDeR reviews in North Central London in 2020 to 2021
- what we learned from the reviews
- what we did to try to make health and social care better for people with a learning disability.

We know lots of people with learning disabilities die younger than other people.

This can be because of health problem they have.

Or because their social or health care was not good enough.

LeDeR was set up to:

- look at the health and social care people had before they died

- use what we find out to try and make services better

- work to make health and social care better so people with a learning disability don't die younger than other people.

About Learning Disability Mortality Review

Bristol University runs LeDeR for NHS England.

LeDeR is one way NHS is finding out how to help people with a learning disability to:

- live longer
- be healthier

LeDeR is very important:

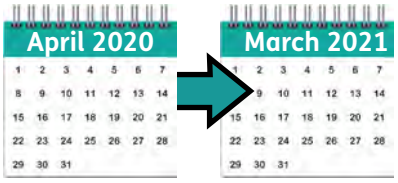
- more people are learning about LeDeR
- it will help make sure people with learning disabilities don't die younger than other people

Local steering groups help to say how LeDeR should work.

There are some plans to see how to include people with learning disabilities in the steering groups.

The deaths LeDeR has been told about

LeDeR need to be told about the deaths of people with a learning disability.



Deaths and reviews between April 2020 and March 2021

LeDeR was told:

- 74 people with a learning disability died
- 58 of these reviews have been finished.

The number of reviews finished is much better than last year.

Some reviews could not be finished:

- there were not enough staff to review during COVID-19
- we are waiting on information
- other reviews must happen first, like a Coroner's review.

Most deaths happened when people were getting sick and dying from COVID-19:

- in early 2020 this was a lot of people
- in early 2021 more work was done to keep people with learning disabilities safe from COVID-19 and we were social distancing.

This was about the same for other parts of England.

If people were men or women

NCL review's told us that:

- 32 people were female
- 42 people were male.

More men died in 2020 than 2019:

- this was because of deaths from COVID-19
- this was the same as other parts of England.

People's age

More people who were between 40-59 years old died in 2020 than in 2019:

- this may be because people in this age group had more medical problems and died from COVID-19 but we are not sure.

37 people who died were over 60 years old.

Where people died

For all of NCL:

- 45 out of 58 people who died were in hospital
- 13 out of 58 of people who died were at home

Last year most people died at their home.

This year:

- most people died at hospital
- people with COVID-19 were getting treatment.

People's ethnicity

LeDeR was told about the ethnicity for most people who died.

42 were White British.

Of the other people who died

- 6 were from a Caribbean background
- 2 other Asian
- 1 other white
- 3 from other groups
- and 4 we don't know.

This is about the same as last year.

Medication people were taking

Stopping overmedication of people with a learning disability, autism or both or STOMP for short, is part of NCL's work.

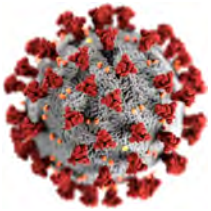
LeDeR asked what medications people were taking when they died:

- 13 out of 58 people were taking antipsychotics
- 14 out of 58 people were taking antidepressants

LeDeR hopes there is more information about medications for the reviews next year.

Why deaths happened

In 2020 to 2021 we found that the largest number of deaths were from respiratory problems (lung problems). 47 people died from this cause.



This year:

- many people died from COVID-19
- many people who died had breathing problems before they had COVID-19
- there were no deaths recorded from the flu. We think this is because people were social distancing and NCL vaccinated many people with learning disabilities
- all of the people who died had 1 long term health problem
- 35 people that died had 3 or more long term health problems. The long term health problems were mostly:
  - with swallowing and breathing
  - epilepsy.

If people had Annual health checks

In the 12 months before people died:

- 64% of people had an Annual Health Check

- 36% of people didn't have an Annual Health Check

This is good news, but more work needs to be done.

LeDeR and COVID-19

During COVID-19 LeDeR:

- sent out information to health workers about COVID-19 and people with learning disabilities

- did quick reviews of people with learning disabilities who died in March and April 2020 to see what could be learned

- did 8 reviews in July 2020 for the national LeDeR report about people with learning disabilities who died from COVID-19.

NCL made changes from what they learnt during COVID-19. They:

- worked with NHS 111 to stop asking if a person who was sick had a learning disability and to stop '**diagnostic overshadowing**'

  Diagnostic overshadowing is a saying a person's new health problem is about the person's disability or other health problems without checking properly.

- gave Oximeters to all NCL places to check if people have enough oxygen even when they might look okay

- shared information better between learning disability teams and health services and worked together more to keep people safe

- made a COVID Grab and Go hospital passport with important health information for people with a learning disability to take with them if the need to go to hospital

- sometimes made reasonable adjustments so family and carers could visit when people with disabilities were in hospital with COVID-19.

NCL told Public Health England and NCL commissioners when there was limited:

- staff testing for COVID-19
- access to Personal Protective Equipment (PPE).

Do Not Attempt Resuscitation Notices

Resuscitate is getting treatment to stop you dying.

It happens when you stop breathing or your heart has stopped.

When people are sick they might ask not to have the treatment. They are allowed to die if they want to.

Doctors need to agree but it must be the person's choice.

If it is agreed a rule can be written down for the person to say do not resuscitate, this is called a Do Not Attempt Resuscitation Notice (DNAR Notice).

During COVID-19 it was found out that many people with disabilities got letters saying they should have a DNAR Notice.

NCL:

- was concerned that people with a learning disability did not feel supported in the way they needed
- will work on making DNAR Notices better in 2022.

Getting good information for LeDeR reviews

A Learning from deaths review:

- collects information about a person, their health and their care
- is also called a Structured Judgement Review or SJR for short.

A Learning from deaths review doesn't always happen. It needs to happen:

- when a person with learning disability dies
- at the same time as telling LeDeR about the death.

It is important because:

- there is better information about the person's care
- it is the best way to work

- we can learn and find ways to do a better job sooner

NCL wants all hospitals to do Learning from death reviews. This will help with LeDeR.

NCL and the Oliver McGowan Independent Review

National LeDeR looked at what the Oliver McGowan Independent Review found. National LeDeR, NHS, LACs and LeDeR reviewers:

- have steps to follow for reviews and meetings
- are making plans for how LeDeR will be run and be checked within ICS. This will happen by April 2022
- will think more about supervision in future changes to how the program works
- LeDeR would like to be able finish all reviews on time. LeDeR would like boroughs to finish actions that are holding up the reviews
- LeDeR will hear more about the Oliver McGowan Training in Learning Disability Autism that everyone will do after the trial period.

Changes to LeDeR

Changes to LeDeR will start on 1 June 2021:

- most deaths will have a basic review. Only some deaths will have a full review when needed or if a family asks
- health and social care services will have the responsibility of reviews
- recommendations from reviews will be agreed by a local panel not the reviewer.

What NCL services did well

NCL Services:

- used pulse oximeters to check if people have enough oxygen even when they might look okay
- used Coordinate My Care (CMC) digital records so health and social care staff had the information to help them in an emergency
- learning disability staff helped families and the person in hospital stay connected when family could not visit
- worked with families to make plans if their family member got very sick before they went to hospital for treatment
- used primary care video checks to work out people's health problems
- GP's took carers concerns about health seriously when a person's behaviour changed. The GP's checked thoroughly to see what might be the health problem
- had monthly Person Centred Planning meetings in the care home including the person in decisions made about them

- helped people to have their favourite items when they were in hospital to help them feel more comfortable
- made reasonable adjustments for a patient needing radiotherapy
- told people about hospice services when they were helping to make end of life care plans
- made sure everyone giving care to a person who was dying knew what their wishes were
- worked with hospice services as soon as this was helpful to provide the best possible care.

What we have learned

What NCL have learnt and will do in 2022

- staff need to follow the Mental Capacity Act to make the best decision when a person cannot decide for themselves, we will work together to improve training

- help more people to use a hospital passport and make an Easy Read guide

- keep working on tools and training for staff to recognise early warning signs of ill health

- more people are getting good primary care. But Annual health checks don't always happen well. We will work on better Annual health checks for more people.

- tell people in an accessible way about health screening appointments

- keep records when a person with a learning disability was not brought to a health appointment

- keep checking and improve training about DNARs to make sure they are used properly.

Credits

This paper has been designed and produced by the EasyRead service at Inspired Services Publishing Ltd.

Ref ISL170 21. November 2021.

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