North East London LeDeR Annual Report 2022 to 2023
Learning from lives and deaths – People with a learning disability and autistic people

Translated into easy read by Ace Anglia: info@aceanglia.com
About this report

This is an easy-read summary of North East London LeDeR Annual Report 2022 to 2023.

We have divided this report into sections to make it easier to read.

The words in blue are ones we think need to be explained more.

We explain what the blue words mean.
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LeDeR stands for learning from lives and deaths of people with a learning disability and autistic adults.

LeDeR is an NHS programme aimed at making services better for people with a learning disability and autism.

When someone with a learning disability or autism dies, their death can be reported to LeDeR to be reviewed.
Anyone can report a death and here is the link to do so:

https://lede.nhs.uk/report

LeDeR looks at many different things when doing a review about a person who has died.

LeDeR looks at what things may have led to someone dying.

What works well with someone’s care and support.
What could have been done differently to make it better for the person and others today.

LeDeR works to stop more people from dying too soon by making care better.

LeDeR works to reduce health inequalities for people with a learning disability and autistic people.
Health inequalities mean some people get poorer healthcare than other people. This happens for many people with learning disabilities and autistic people.

LeDeR looks at lives and deaths of people with learning disabilities aged 4 and above.

This includes people with both learning disabilities and autism.
From January 2022, the LeDeR programme has started looking at the deaths of autistic adults.

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

The LeDeR programme has been going since 2017.
Every year we must write a report.

This year’s report is about the people who died, and their reviews completed between 1st April 2022 and 31st March 2023.

This is the 4th annual report of the NHS North East London LeDeR programme.

This is the first LeDeR annual report written by North East London Integrated Care Board.
An **Integrated Care Board** is a NHS organisation set up by the government to develop health plans to meet the needs of people in their local area.

They are also responsible for spending money on carrying out plans in their local area.
Chapter 3: About the people who died

When a person with a learning disability or an autistic adult dies, LeDeR is told about their death. This is called a notification.

Between 1st April 2022 and 31st March 2023 NHS North East London received a total of 126 notifications.

- Redbridge- 27
- Newham- 24
- Barking & Dagenham- 21
- Havering- 18
- Tower Hamlet- 14
- City & Hackney- 13
- Waltham Forest- 9
Age of people who died

95 people were adults.
Adults are people aged 18 and over.

31 people were children.
Children are people aged between 4 and 17.
Gender of people who died

52 people were male.

52

48 people were female.

48

Reviews that were completed
There are 2 different types of LeDeR reviews:

**Initial Review** – first check to see if there is anything that can be learned from the lives and deaths of people.

**Focused Review** – a more detailed look than the initial review of a person’s care.
62 initial reviews were completed.

25 reviews were focused reviews.

33 reviews are still being done.
18 reviews have not started.

This report will go through the information about 62 people who had their care reviewed.

53 people had a learning disability.
8 people had both a learning disability and autism.

1 person was autistic.

Level of Learning Disability
We use four main groups to describe what type or level of learning disability people had.

- 16 people had a **mild learning disability**. They may have needed **some support in a few** of daily living activities.

- 20 people had a **moderate learning disability**. They needed support in **more** activities of daily living.
18 people had a severe learning disability. They needed support with almost all of daily activities.

5 people had a profound/multiple learning disability. They needed support in all activities of daily living.

This information for 3 persons was not taken.
Ethnic backgrounds

Ethnic background means anyone not from a White British background.

43 people were from a white background.

19 people were from a Black, Asian, and Minority Ethnic background, also known as ‘global majority’
• 4 people were from an Indian ethnic background

• 2 people were from a Pakistani ethnic background

• 4 people were from a Bangladeshi ethnic background
• 2 people were from an African ethnic background

• 3 people were from an African-Caribbean background

• 3 people were from other ethnic backgrounds
• We do not know the ethnic background of 1 person

Places of death

41 people died in hospital.
18 people died in the place they lived.

4 people died in a hospice – a home providing care for the sick or terminally ill or approaching the end of life.

8 people died in their place of choice, and all had end-of-life care in place.

End-of-life care means when a person is likely to die within the next 12 months.
They died either at their family home, hospice or long-term placements.

They died surrounded by family, friends and staff whom they had known for a long time.

4 people died not in their place of choice. Their wish was to die in their own homes.

From the information we had collected, it was not possible to know whether 50 people died in their place of choice or not.
Chapter 4: Long Term Conditions

Long term health conditions are health problems that cannot be cured but can be managed or controlled by medicines and therapies.

The people who had died were known to have had 2 or more long term health conditions

13 people had Epilepsy
A condition that affects the brain and causes frequent seizures or fits

9 people had mental health conditions
Conditions that affect a person’s mood, thinking and behaviour, such as depression or anxiety.
10 people had heart-related problems
Their heart was not working as it should.

4 people had sensory impairments
Conditions that affect how well someone can hear or see.

5 people had swallowing problems
Found it difficult to swallow food and drink which caused them to cough or choke.
Chapter 5: Causes of deaths

This chapter is about what the causes of deaths were for the people we reviewed.

People with a learning disability are more likely to die of avoidable causes compared to the general population.

Avoidable causes are those deaths that could have been prevented or treated if found early.

Approximate 47% of all deaths recorded were avoidable.
People died from problems or conditions that could have been treated or prevented if they were found in time such as sepsis and cancer.

24 people died from respiratory conditions
Breathing problems where the lungs cannot get enough air.

12 people died from cancer
A disease caused by unusual cells in a part of the body.

12 people died from heart-related problems
When your heart is not working as it should such as blood pressure, or poor heart movements.
8 people died from sepsis
when infection get into the blood system and your body is unable to get rid of it causing damage to tissues and organs.

7 people died from covid-19
a virus with symptoms similar to those of flu but more severe and could cause death.

5 people died from renal failure/acute kidney injury illness or problems related to your kidneys.
4 people died from a heart attack
A condition where blood is suddenly blocked from getting to the heart.

3 people died from epilepsy
Epilepsy is a common long-term condition that affects the brain and causes frequent seizures or fits.

2 people died from diabetes
A lifelong condition that causes a person's blood sugar level to become too high or too low.
Chapter 6: Care provided to people who died

This chapter is about the different care provided to people who died.

Annual health checks

An Annual Health Check is a yearly check up at the GP’s surgery.
People with a learning disability aged 14 years or older can get an annual health check.

Having annual health checks every year can help spot unknown health conditions early.

This can mean people can be referred for early treatment or stop a person from getting too unwell.

56 people were over the age of 14 and could have an annual health check.
38 people got an annual health check in the last 18 months.

18 people did not have an annual health check in the last 18 months.

The doctor or nurse doing annual health checks is expected to do a face-to-face appointment.
10 people got a face-to-face appointment.

14 people got a telephone or video appointment.

We do not know the type of appointment for 14 people, as this was not recorded by the doctor.
Most families were not happy with a telephone and video appointments.

This was because the doctor or nurse could not do any tests and observations by telephone.

At the end of an annual health check, a doctor or nurse should fill out a health action plan.

Health action plan is a record of a person’s health and give information about what that person needs and wants to do to stay healthy.
A good health action plans should have goals to work toward to

Health action plan also gives carers information on what to do to support the person to stay well and healthy.

This is usually reviewed during the next annual health check appointment and new targets agreed.
14 people got a Health Action Plan.

Most carers we asked about health action plans did not know whether the person they cared for got one or not.

Carers are encouraged to ask their doctors for a health action plan at the end of an annual health check.
Records show more people are attending annual health checks, but the quality is not as good as it should be. Therefore, annual health checks need to be improved to benefit the person.

NHS England recommends face to face annual reviews.

A good annual health check should be able to spot unknown health problems early and do something before they get worse.

Weight management
LeDeR programme continues to monitor the weights of people with a learning disability and autistic people.

They are more likely to be overweight and or obese compared to people without a learning disability and autism.

Being overweight or obese means having more fat in your body than you need. Having more fat than you need can cause health problems.
More people are now being weighed compared to last two years.

Fewer people were obese compared to 2021/22.

More people were overweight compared to 2021/22.
More people were recorded as underweight. This means they did not have enough fat in their bodies that they needed.

Across North East London, there are a number of projects aimed at improving health and wellbeing of people with a learning disability and autistic adults.

Fewer people were recorded obese this year compared to last year, 2021/22.
We will continue to look at the results of these projects and record any changes.

**Mental Capacity Act and mental health issues**

**Mental Capacity Act** is a set of government laws that protects people who are unable to understand information and make some decisions about their lives.
Questions about mental capacity assessment are asked in a focused review.

A mental capacity assessment is an evaluation used to find out whether a person has the ability to make decisions.

25 people had a focused review.
20 people had a mental capacity assessment.

5 people did not have a mental capacity assessment.

It was found that the people who did not have a mental capacity assessment may have needed one.
They said no to treatment which may have helped them and likely to have had an impact on their health and wellbeing.

Some professionals and carers may not have understood Mental Capacity Act and how it benefits the person and those caring for them.

10 people had Deprivation of Liberty Safeguards (DoLs).
Deprivation of Liberty Safeguards (DoLs) is a set of rules to protect a person receiving care.

Deprivation of Liberty Safeguards (DoLs) are used in hospitals and residential and nursing care places.

For people living in own homes or supported living, require Court of Protection application.

They were applied for people who were unable to make decisions about the care and treatment they need.
Flu vaccination

The Flu vaccination is usually injections given to people to prevent them from getting very ill if they get flu.

The flu vaccination is offered yearly to some people to protect them from getting extremely ill from flu.
All **62 people** we reviewed could have had a flu vaccination.

**49 people** had a flu vaccination.

NEL (North East London) has seen an increase in Flu jab uptake since 2020. This is higher by 18% compared to last year, 2021/22.
Covid-19 vaccination

4 people had 1 dose of COVID-19 vaccination

46 people had 2 COVID-19 doses and a booster vaccination.
A small number of people (4 declined) did not have the COVID-19 vaccination because they had a fear of needles.

1 person who did not have the COVID-19 vaccination died of COVID-19.

Suggestions were made around making sure people with a learning disability understand the importance of taking COVID-19 vaccination.
This will help reduce the risk of them getting COVID-19 and protect them from serious illness.

We need to help people with a fear of needles so they can have vaccinations.

Cancer screening
Cancer screening are tests done by health professionals to find out if someone has cancer or not.

Cancer screening is important in spotting cancers early and making sure treatment is given in good time.

In North East London a lot of people are still dying because of cancers.
Research show that recovering from cancers continue to improve if spotted early.

NHS bowel cancer screening checks for bowel cancer.

It is available to everyone aged 60 to 74 years.
24 people aged over 60 years old could have bowel screening.

8 people got bowel cancer screening.

2 people died of bowel cancer, 1 of the people had not heard bowel screening.
Cervical screening check for cervical cancer in women.

Cervical screening is for women aged **25 to 64 years**.

**10 women** could have cervical screening.
3 women got cervical cancer screening This number is far less than those without a learning disability and autism.

Breast cancer screening checks for breast cancer.

It is available to women aged 50 to 70 years.
16 women could have breast cancer screening.

6 women got breast cancer screening.

The number of people we reviewed who got cancer screening is a lot less compared to the general public.
We have seen small improvement in uptake with people with learning disability in 2022/23.

We need to improve awareness of cancer screening.

It is important that people, carers and care staff recognise the importance of cancer screening in finding and treating cancer early.
Information needs to be provided in a way a person can understand such as easy read, pictures, big print and audio.

More support is needed to make sure people with a learning disability and autism understand screening and attend appointments.

End-of-life planning
37 people had end-of-life plans in place before they died.

End-of-life plans are plans to care for and support people who are in the last months or years of their life.

Most of the end-of-life plans were made during the person’s last stay in hospital.

The end-of-life teams provided very good care and families felt supported during these difficult few days or months.
4 people died before they could be put on an end-of-life plan.

We want to continue our support on training staff to spot when someone is getting worse and refer them early to end-of-life teams.

We want our staff to talk about end-of-life with the person, families and carers.

And write down their wishes and carry them out where possible.
Do Not Attempt Cardiopulmonary Resuscitation

Do Not Attempt Cardiopulmonary Resuscitation is shortened to DNACPR. It is a decision for some people that tells their healthcare team not to restart their heart or breathing if it stops.

A DNACPR decision is put in place to protect people from unnecessary suffering from restarting their heart or breathing.
There are rules all professionals must follow when making a DNACPR decision.

38 people had DNACPR in place before they died.

Most families and other care professional were involved in this decision.
1 person had a DNACPR decision removed because the family did not want it.

2 people had a DNACPR decision removed because the reason given was a learning disability.

The NHS is clear that people should not have a DNACPR decision just because they have a learning disability, autism or both.
We want more people to have an **Independent Mental Capacity Advocate** to help and support them through difficult decisions.

An **Independent Mental Capacity Advocate** is a person trained to support people who are not able to make certain decisions for themselves due to lacking mental capacity.

Examples of decisions includes where a person would like to live and about serious medical treatment options.
Independent Mental Capacity Advocate can help support people with important decisions such as DNACPR and end-of-life.

Reasonable adjustments are changes to services, so they are easier to use by people with a disability.
Almost all people with a learning disability and autism need support in accessing and using services in one way or the other.

It is everyone’s responsibility to provide reasonable adjustments to everyone who needs this.

Good assessments help identify the right support people need.
Information from completed reviews showed that some reasonable adjustments were provided when needed.

Some people did not get the right reasonable adjustments in good time.

1 person got a wheelchair their carer was unable to push.
Not getting the right reasonable adjustments means people cannot access good health care.

Lack of or poor provision of reasonable adjustments could lead to or contribute to avoidable deaths.
Emergency Departments and Urgent Care Centres

People with learning disabilities are more likely to have a wide range of physical and mental health problems.

This means they are more likely to go to Emergency Departments or Urgent Care Centres more times than other people.
We have found a lot of things that worked well at Emergency Departments or Urgent Care Centres.

For example, some people got support from the learning disability and autism nursing teams and very good treatment when seen.

We have found some things that did not work well at Emergency Departments or Urgent Care Centres.
For example, people in pain due to long waits.

Also, some people who could not tell staff about their pain because they did not speak.

We want health professionals to take detailed assessment of the person
and consider any changes in behaviour may be due to pain.

We want health professionals to get support from learning disability teams as needed.

We want senior health professionals to make sure a person is safe to go home.
Chapter 7: The quality of care a person received

The information about how good someone’s care was is based on 25 focused reviews.

12 people got good or excellent care.

10 people got satisfactory care.
Satisfactory care means the care was mostly good but some things could have been better.

2 people got care that was not as good as it should have been.

This may have had an impact on their wellbeing.

1 person got care that was not good.

This had an impact on their wellbeing and may have played a part in the person’s cause of death.
This review was passed on to a **safeguarding** team to look into.

**Safeguarding** means protecting peoples’ rights and taking actions to ensure they have good health and free from abuse and neglect.

People with mild to moderate learning disabilities and autism were more likely to receive poor care.

Some reasons why include—
• They are less likely to go to annual health checks and medical reviews.

• They are more likely to have health needs that are not known, which could otherwise be picked up during annual health checks.

• They are less likely to benefit from community learning disability services.
• They are more likely to develop mental health problems

• They are expected to find their way into and around health and care services like any other person without a learning disability or autism which can be a struggle
Chapter 8: What we did well

We have learned a lot about what was good about people’s care.

Some good examples are:

- Good quality annual health checks leading to referrals and early treatment.

Good health action plans to support people with health and social care issues
- Good communication between professionals, families and people

- Evidence of good understanding and carrying out of Mental capacity act

- All services show they are always learning how to do better
• Good working relationships between learning disability teams, families and community teams

• Some GPs provide home visits

• Some GPs provide long appointments
• Good social care packages meeting the person’s health and social care needs.

• Joint meetings between different professionals to support patients with a lot of different care needs

• Excellent reasonable adjustments provided in good time
Chapter 9: What needs to be better?

- Staff were good at carrying out protocols

Protocols are rules around how a professional must do something.

- Excellent end-of-life care and support for people and their families
The report has found out what needs to be done better about people’s care. Some of the areas people want to see improved are-

- Annual health checks spotting unknown health issues

- Making referrals to other services in good time
• Contact people if they have missed appointments

• More face-to-face appointments; no telephone or video appointments, except if the person is happy with this

• More home visits for people with poor mobility or unable to leave their homes.
• Longer appointments and during times suited to the person

• Home adaptations done quicker

• More people to be referred for Mental Capacity Assessments and support provided as guided by the assessment report
• More professionals using or referring to Independent Mental Capacity Advocate services

• Provide equipment that is right for the person’s needs. For example, a wheelchair the person can use

• Good care plan for when people leave hospital to get better quicker at home
• Timely referrals to end-of-life care teams and support for people and their families to make these decisions

• Provide information in a way people can understand. For example, easy read or another language.

• Closer working relationships between learning disability services and other professionals

• Greater need to promote use of hospital passports or urgent care plans or both.
Chapter 10: Going Forward

- Welcome more organisations, people, and their families to take part in our North East London LeDeR working groups
- Continue awareness of LeDeR and sharing findings from completed reviews
- Working better with our health and social care partners and care providers.
• Continue promoting rights and making sure that the needs of autistic people are known.

• Promote open approaches or ways of learning and understanding the needs of people with a learning disability and autistic people.

• Making it known that it is everyone’s duty to provide or ask for reasonable adjustments to be provided.
For further information about this report please contact Beatrice Kivengea by email: beatrice.kivengea@nhs.net

For other queries, LeDeR email: nelondonicb.lederprogramme@nhs.net

North East London details:
NHS North East London Integrated Care Board (ICB)  
LeDeR Programme  
4th Floor Unex Tower,  
5 Station Road,  
London E15 1DA

This document was translated into easy read by Ace Anglia.

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Facebook: Ace Anglia  
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Twitter: @aceanglia  
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