

This easy read report is from:

NHS Nottingham and Nottinghamshire Integrated Care Board.



It tells you about the:

## LeDeR Programme Annual Report 2024-2025



What is LeDeR?



People with Learning Disabilities and Autistic people sometimes die too early from conditions and illness that could have been stopped.



The NHS has been asked to look at all the deaths of people with a Learning Disabilities and Autistic people.

The LeDeR teams are responsible for making this happen..



When someone with a learning disability or an autistic person who is 18 or older dies, LeDeR people look at what happened.



LeDeR looks at how we learn from the lives and deaths of people to help us improve care.



We write reports to show what is being done to improve the care of people with Learning Disabilities and Autistic people.



We have a team of people with the skills to improve the lives of people with Learning Disabilities and Autistic people who use health services.



The report tells us what we need to understand to help stop people with Learning Disabilities and Autistic people from dying from something we could stop.



LeDeR reviews



By asking questions about the lives and deaths of people with Learning Disabilities and Autistic people, we learn where we need to make changes and improvements.



Jo and Sarah are LeDeR reviewers.

They write down what people tell us onto a special form called a review.





We get answers to our questions about the person who has died by talking to:

- Families
- Friends
- Carers
- Doctors

Together, we look at the reviews and how we can learn from them.



What do we need to do better?

We need to be better at:



 Moving people from Children & Young People services to adult services.



- Learning disabilities registers so we know who has a Learning Disability.
- Autism registers, so we can tell if a person is autistic.



• Be better at stopping chest, lung, heart problems, epilepsy and cancer.



 Talking and sharing information between GP's nurses, hospitals, care homes and social workers.



 Offering support and teaching for Carers and Families.



What we learn from the reviews is passed on to those who provide care and support to people and their families.



This means that people who give care and support can use what we learn to help make their care and support better.



What do we know about deaths in Nottingham and Nottinghamshire?

The largest number of Learning Disabilities and Autistic people died from problems with:

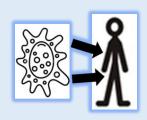


• Breathing (Pneumonia and Covid).

The next biggest causes of death were:



Heart



• Serious infections (Sepsis)



 Large blood vessels which help to move blood around your body



Cancer

Brain bleed



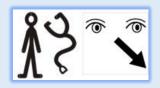
Epilepsy



We think that by making support and care better for people less will die too early from conditions that could have been stopped.



What are we doing to make things better?



We have told doctors, nurses, carers, social workers and our team that we must be better at noticing when things go are wrong.



Noticing when things start going wrong early on will help people get the best care.



One way of noticing problems early on is to ask people to have a health check every year at the GP's.



For someone with a Learning Disability this is called an **Annual Health Check.** 



Good things that happening across Nottingham and Nottinghamshire.



 Better access to doctors and hospital records which will help to make a good review. A good review will make care staff think about better ways to care for people with Learning Disabilities and Autistic people.



 About 7 in 10 people with learning disabilities are getting Annual Health Checks. This number is getting bigger.

We are one of the top areas in the East Midlands for the number of people having these checks.



 Nurses are working with G.P's to make sure that they can see on their computer system who has a Learning Disabilities and what support they need.

## We are going to:



 Make our computer system help us to learn how we can make support and care better so that fewer people die.



 Include the lives and deaths of Autistic people and learn from what we find.



 Teach more people in health and care and in the community about the needs of people with Learning Disabilities and Autistic people.



 Help the places where people live and work to be better at meeting their needs.

We always want to do better for people with Learning Disabilities and Autistic people and their families.



To help make this happen we will make sure anyone who works with people with Learning Disabilities and Autistic people and their families are all speaking to each other at meetings and by email.



Have your say.

We would like to hear what you, your family and friends think too.



You can contact the NHS Nottingham and Nottinghamshire LeDeR Programme Team by email:

nnccg.lederprogramme@nhs.net



You can contact the LDA (Learning Disability and Autism) Expert by Experience Group.

This group is for families, carers, and patients. It is a place to meet where people support each other



You can contact the group by email to find out more. nnicb-nn.nottinghamshireLDA@nhs.net



Jonathan Sansome, (Quality and LeDeR Programme manager), along with Kirstie Charlesworth (LeDeR Programme administrator) runs the LeDeR Programme in Nottingham and Nottinghamshire.



Thank you for reading our report.

The Nottingham and Nottinghamshire LeDeR Team.