

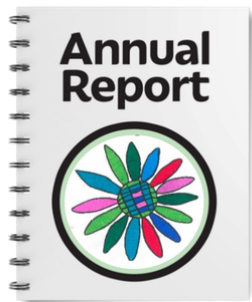
LeDeR 2024

Learning from lives and deaths: People with a learning disability and autistic people



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What is this report about?



This report tells you what LeDeR reviews learnt about people with a learning disability in England who died in 2024.

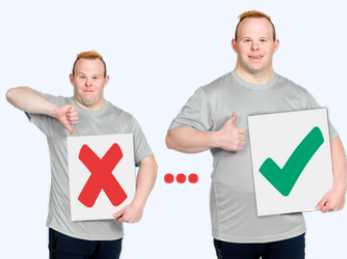


What is LeDeR?



Every year, LeDeR reviews look at the deaths of people with a learning disability and autistic people.

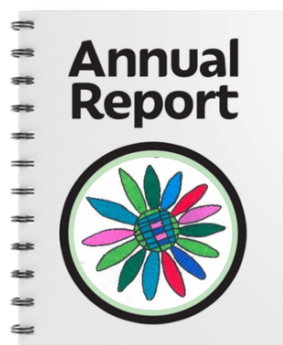
We want to learn from this.



We hope that it helps to make care better for people with a learning disability and autistic people.



This report is about three thousand, three hundred and ninety five (3,395) people with a learning disability in England who died in 2024



What is in this report?



How old were people
when they died?

Page 5



Avoidable deaths

Page 7



People with different kinds
of learning disability

Page 10



People with down
syndrome

Page 17



How old were people when they died?



Many people **with** a learning disability were not very old when they died.



The average age of death for people **with** a learning disability was 63 years.

This means that:

- Half the people who died were **younger** than 63.
- Half the people who died were **older** than 63.



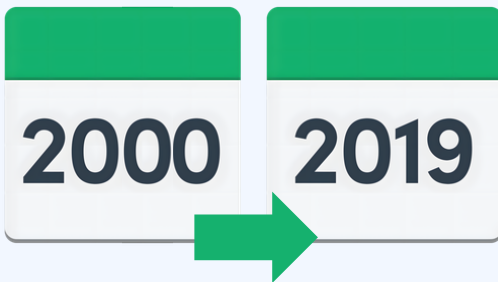
Many people **without** a learning disability lived much longer.



The average age of death for people **without** a learning disability was 82 years.

This means that:

- Half the people who died were older than 82.
- Half the people who died were younger than 82.



People **without** a learning disability lived 19 years longer than people **with** a learning disability, on average.



Avoidable deaths



An avoidable death is when people die of an illness that can usually be stopped or treated.



Maybe, something could have been done to help people live longer.

2x



People **with** a learning disability were almost twice as likely to die an avoidable death as people **without** a learning disability.



Are all deaths avoidable?



No, some people die from illnesses that cannot usually be stopped or treated. These deaths are not avoidable.



Why did avoidable deaths happen?



Some people died of an illness that can usually be treated.



For example, some people who died from epilepsy might have lived longer if they had an epilepsy care plan or the right medication.



Why else did avoidable deaths happen?



Something could have been done to stop some people from getting the illness that they died from.



For example, some people who died of flu might not have died if they had the flu vaccine.



Some people who died from heart disease might not have died if they were supported to exercise and eat healthy food.



People with different kinds of learning disability

All people with a learning disability are different.



Many people with a learning disability need help in their lives. People with a severe or profound learning disability need the most help.



People with a mild or moderate learning disability can do more things without help.



What did we learn about people with a severe and profound learning disability?

People with a severe or profound learning disability were most likely to die of:



- illnesses of the nerves or brain (for example, epilepsy)



- lung problems



- conditions they were born with



What can we do about this?



People with a learning disability may need:

- specialist support



- the right treatment at the right time

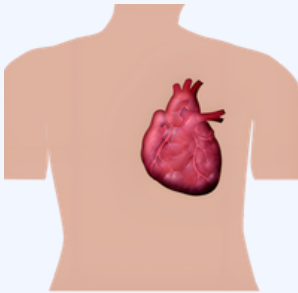


This is important for everyone. It can be especially important for people with a severe or profound learning disability.

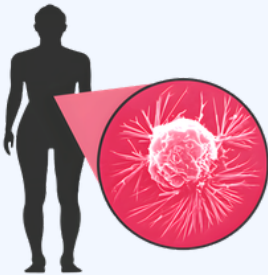


What did we learn about people with a mild or moderate learning disability?

People with a mild or moderate learning disability were most likely to die of:



- heart problems



- cancer



- lung problems



What can we do about this?



People with a learning disability may need support to:



- live a healthier life



- have regular health checks



This is important for everyone. It can be especially important for people with a mild or moderate learning disability.



Did all groups of people get good care and reasonable adjustments?



Reasonable adjustments are changes that services must make to how they do things, to make it easier for the person with a learning disability.



Most people with a severe or profound learning disability had reasonable adjustments and the right support for their needs.



But people with a mild or moderate learning disability were less likely to get the right support for their needs.



People with a mild or moderate learning disability were less likely to have the reasonable adjustments they needed.



What can we do about this?



Make sure everyone gets the right care and enough support



Make sure everyone gets the reasonable adjustments they need.



People with down syndrome



People with down syndrome died 4 years younger than other people with a learning disability, on average.



People with down syndrome were most likely to die of:

- dementia
- illnesses of the nervous system (for example, epilepsy)





We have reached the end of the report.



Is there anything you can do about all this?



If you feel unwell or notice any changes in your health, make sure you:

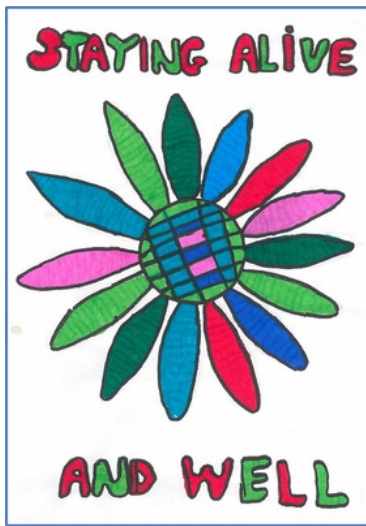
- tell someone you trust



- talk to a doctor or nurse as soon as you can



If you feel upset after reading this report, it can be helpful to talk with someone you trust.



This is an easy-read version of the full 2024 Annual Report LeDeR: Learning from Lives and Deaths: People with a learning disability and autistic People. This report was written by the Staying Alive and Well Group.

The following versions of this report are available here:

www.kcl.ac.uk/research/leder



- The full 2024 Annual Report
- A video version of this easy-read report
- A video of the foreword



We are a group of people who have a learning disability or who are autistic, meeting at Kingston University London: Richard Keagan-Bull, Maggie Brennan, Amanda Cresswell, Frankie Cutri, Joanne Kennedy, Andrew Meyer, Sonia Reed, Lee Scott, Mark Shackleton.



We were supported by: Irene Tuffrey-Wijne, Jonathon Ding (Kingston University), David Mahon (Foundation for People with Learning Disabilities), Andrew Redmayne, Janice Wycherly and Dene Donalds (Pathways Associates), Rosie Cammack (Estia Centre) and Emma Pierssene (Learning Disability Partnership Board – East Sussex).



The Staying Alive and Well group is a co-production partnership. We are part of a collaboration led by King's College London, supporting NHS England.