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

2022
This report has 7 parts.
Each part has a different colour.
The grey part:
Who died, and how old were they?

The yellow part:
What did people with a learning disability die of?

The blue part:
How good was the care for the people who died?

The green part:
Which people with a learning disability were more likely to die younger?

The orange part:
Could more people with a learning disability have lived longer?

The pink part:
COVID-19 and Heatwaves

The purple part:
Autistic people without a learning disability
The grey part
Who died in 2022 and how old were they?

We heard about 3,648 people with a learning disability who died in 2022.

Of each 10 people with a learning disability who died...

6 were men
4 were women
Of each 10 people with a learning disability
4 were still alive at the age of 65

But of each 10 people who don’t have a learning disability, 9 were still alive at the age of 65

It means that people who have a learning disability don’t live as long as people who don’t have a learning disability

Men with a learning disability usually died 20 years earlier
And women usually died 23 years earlier
Of each 10 people with a learning disability who died...

- 6 died in hospital
- 3 died at their home
- 1 died somewhere else

Most people we heard about, who died, were white.

We need to learn more about the people from minority ethnic backgrounds who died.

- Black people
- Asian people
- People from mixed backgrounds
- Other people who are not white.
What did people with a learning disability die of in 2022?

Of each **100 people** with a learning disability who died this is what they died of:
Of each 100 people with a learning disability who died:

- 13 died of health problems that they have had all their lives, from when they were babies.
- 11 died of cancer.
- 8 died of flu and lung infections (pneumonia).
- 6 died of cerebral palsy and paralysis.
- 6 died of heart problems.
- 6 died of COVID-19.
- The others died of all sorts of other things.
Most people with a learning disability (9 out of 10) had some care which was good.

This doesn’t mean that all their care was good, but at least some of it was good.

But some people (1 out of 10) did not have any good care.

We spot a difference here!

Last year, 3 out of 10 people did not get any good care.

This year, it is 1 out of 10.
What was good about people’s care?

Reasonable adjustments are changes staff can make to help people cope with their care and treatment.

For example:
- More time
- Easy to understand information
- A calm place to wait

Reasonable adjustments helped people get good care.

Staff working together and working with families helped people get good care.
What problems were there about people’s care?

People were waiting too long to get tests and treatments.

Doctors and nurses were not doing mental capacity assessments properly.

A mental capacity assessment is when they check to see what you understand.
People who didn’t get good care and treatment

For example, they didn’t get a COVID vaccine

They were more likely to die younger

People with epilepsy

were more likely to die younger

People from black, Asian or mixed backgrounds

were more likely to die younger
The orange part
Could more people with a learning disability have lived longer?

Some people died before their time.

Perhaps they could have lived longer if they had got better treatment and support.

For example, by:

- Treating an infection
- Managing epilepsy well
Or perhaps they needn’t have got ill in the first place.

For example, by:

Getting a vaccine  Checking for illnesses

This is called **avoidable death**.

It means: dying of something that nowadays, you shouldn’t have died of.
Almost half of all the people with a learning disability who died, died an avoidable death.

But of all the people without a learning disability who died, less than a quarter died an avoidable death.
This means that people with a learning disability are **twice as likely** to die before their time.
This chapter is NEW

COVID-19

In 2022, fewer people with a learning disability died of COVID-19 than the year before.

But they were still more likely to die of COVID than people who don’t have a learning disability.

So, people with a learning disability still need to be at the top of the list for vaccines.
Heatwaves

Lots of extra people with a learning disability died in July

This was because of a heatwave

This means people with a learning disability need extra protection from the heat
This chapter is NEW

The deaths of all autistic people can now be reported to LeDeR. Even if they don't have a learning disability.

This is NEW

We only heard about 110 autistic people without a learning disability who died in 2022.

We need to know more about autistic people without a learning disability so we can learn from their deaths.
This is an Easy-Read version of the full 2022 Annual Report LeDeR: Learning from Lives and Deaths – People with a Learning Disability and Autistic People.

The following versions of this report are freely available here: www.kcl.ac.uk/research/leder

- The full 2022 Annual Report
- A video version of this Easy-Read report, plus a video of the foreword
- PowerPoint slides of this Easy Read report

This report was written by the Staying Alive and Well Group.

We are a group of people who have a learning disability or who are autistic, meeting at Kingston University London:


We were supported by:

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