LeDeR
Learning from lives and deaths:
People with a learning disability
and autistic people
2021
This report has 6 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 with a learning disability 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: How did COVID affect people with a learning disability?
There is nothing on this page.
The grey part
Who died in 2021, and how old were they?

We heard about 3,304 people with a learning disability who died in 2021

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

6 were men
4 were women
Of each 10 people with a learning disability who died:
6 died before their 65th birthday

People younger than 65 when they died
People older than 65 when they died

Of each 10 people who don’t have a learning disability,
only 1 died before their 65th birthday

People younger than 65 when they died
People older than 65 when they died

People with a learning disability usually died 22 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.
Of each 100 people with a learning disability who died in 2021, this is what they died of:
20 died of COVID-19

11 died of cancer

9 died of health problems that they have had all their lives, from when they were babies

7 died of flu and lung infections (pneumonia)

4 died of cerebral palsy and paralysis

4 died of heart problems

4 died of stroke

3 died of dementia

2 died of epilepsy

The others died of all sorts of other things
The blue part

How good was the care for the people with a learning disability who died?

Most people with a learning disability (7 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 (3 out of 10) did not have any good care.
What was good about people’s care?

Annual health checks helped people get good care.

Learning disability liaison nurses helped people get good care.

They are special nurses who understand what people with a learning disability need.
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
The green part
Which people with a learning disability were more likely to die younger?

People with epilepsy were more likely to die younger.

People from minority ethnic backgrounds were more likely to die younger.

This means that many white people with a learning disability lived longer than people that were black, Asian or mixed backgrounds.
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.
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 more than twice as likely to die before their time.
6. The pink part
How did COVID affect people with a learning disability?

In March and April 2020, lots more people died than usual. This was because of Covid-19.

People with a learning disability were more at risk of COVID-19.
Lots of extra people who don’t have a learning disability died in March and April 2020.

But the number of extra people with a learning disability who died, was double.

Very few fully vaccinated people with a learning disability died of COVID-19.

The Covid vaccine stopped many people dying.
This is an Easy-Read version of the full 2021 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 2021 Annual Report
- A video version of this Easy-Read report
- 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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