

Kingston University
London



Made with PhotoSymbols™

LeDeR

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

2021



This report has **6 parts**.

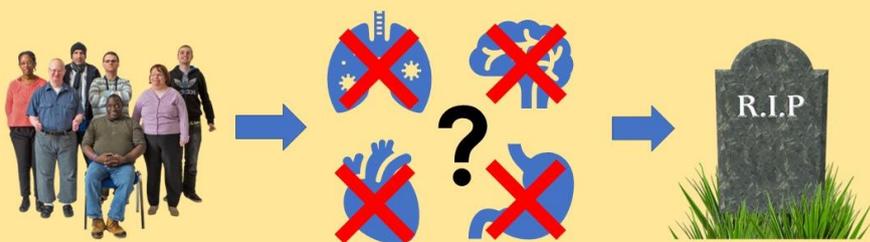
Each part has a **different colour**.





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:

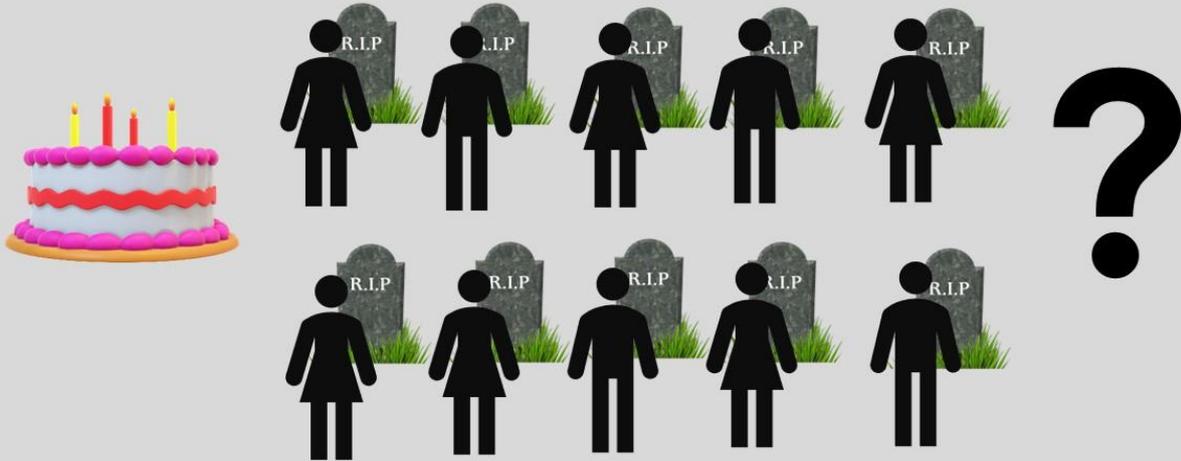
How did COVID affect people with a learning disability?



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

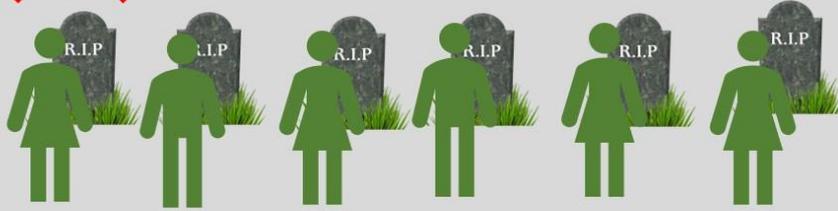


4 were
women

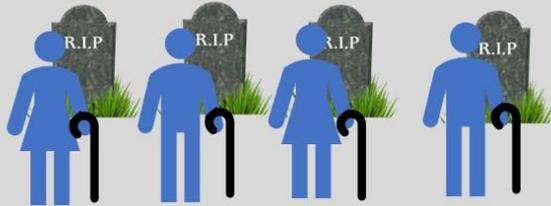




Of each **10 people with a learning disability** who died:
6 died before their **65th birthday**



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**



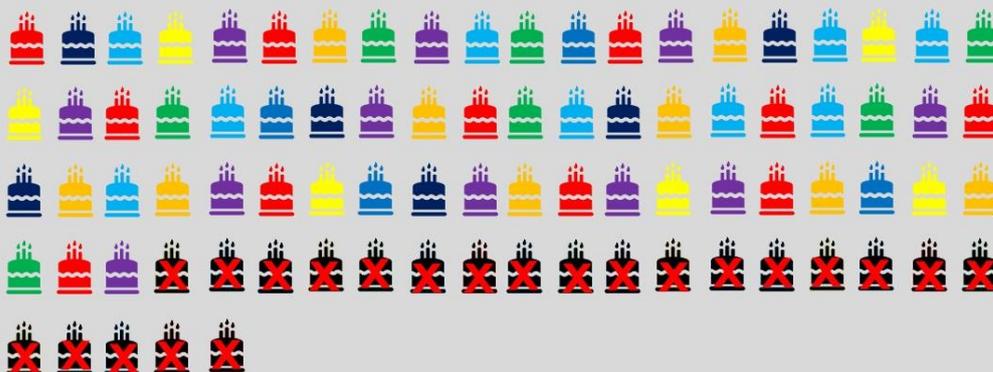
People **younger than 65** when they died



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...



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



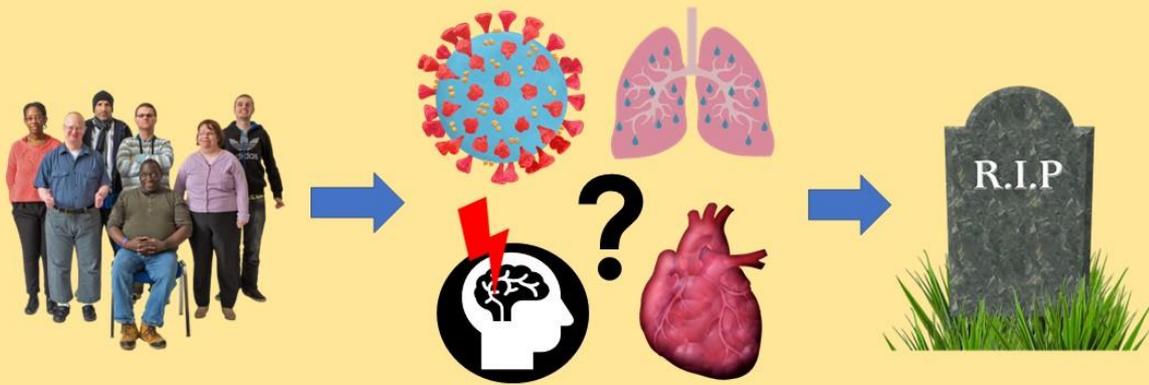
We need to learn more about the people from
minority ethnic backgrounds who died.

Black people
Asian people
People from mixed backgrounds
Other people who are **not white**.

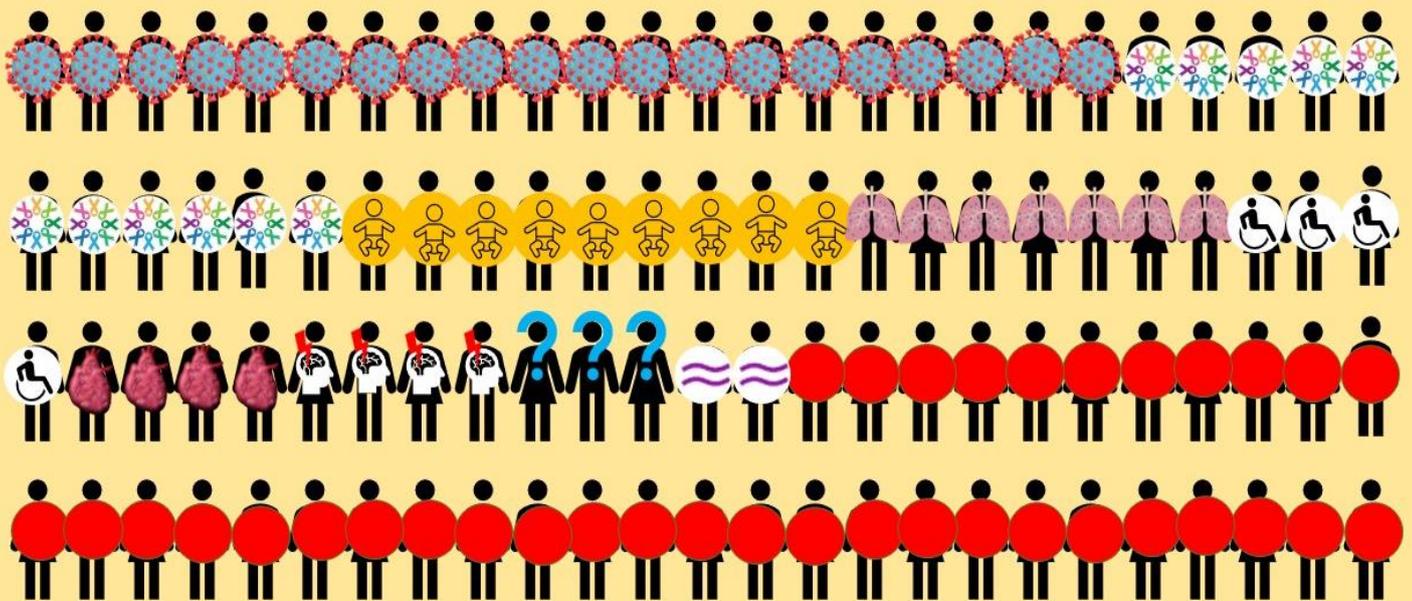




The yellow part What did people with a learning disability die of in 2021?



Of each **100 people**
with a learning disability who died



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**



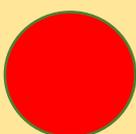
4 died of **stroke**



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



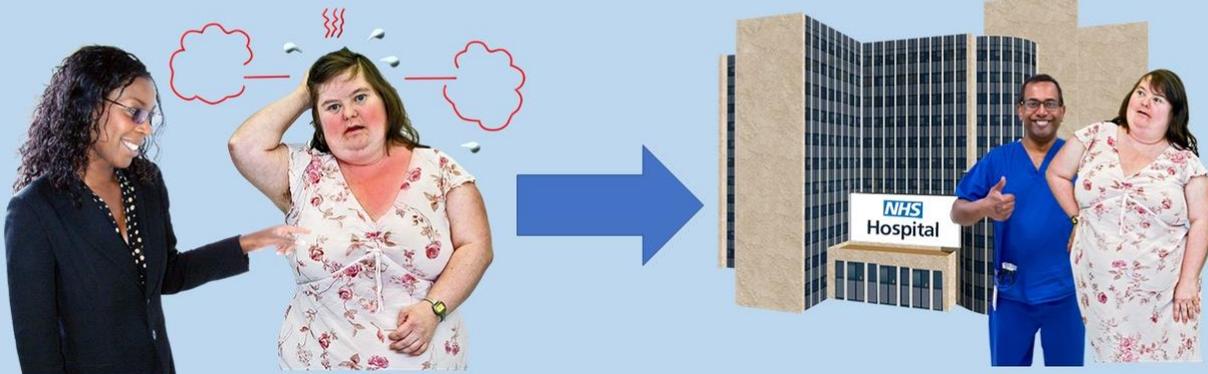
They are special nurses who understand what people with a learning disability need



What problems were there about people's care?



Sometimes, carers found it difficult to notice people were ill.



Sometimes, staff didn't make **reasonable adjustments**



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?

2021



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?

2021



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



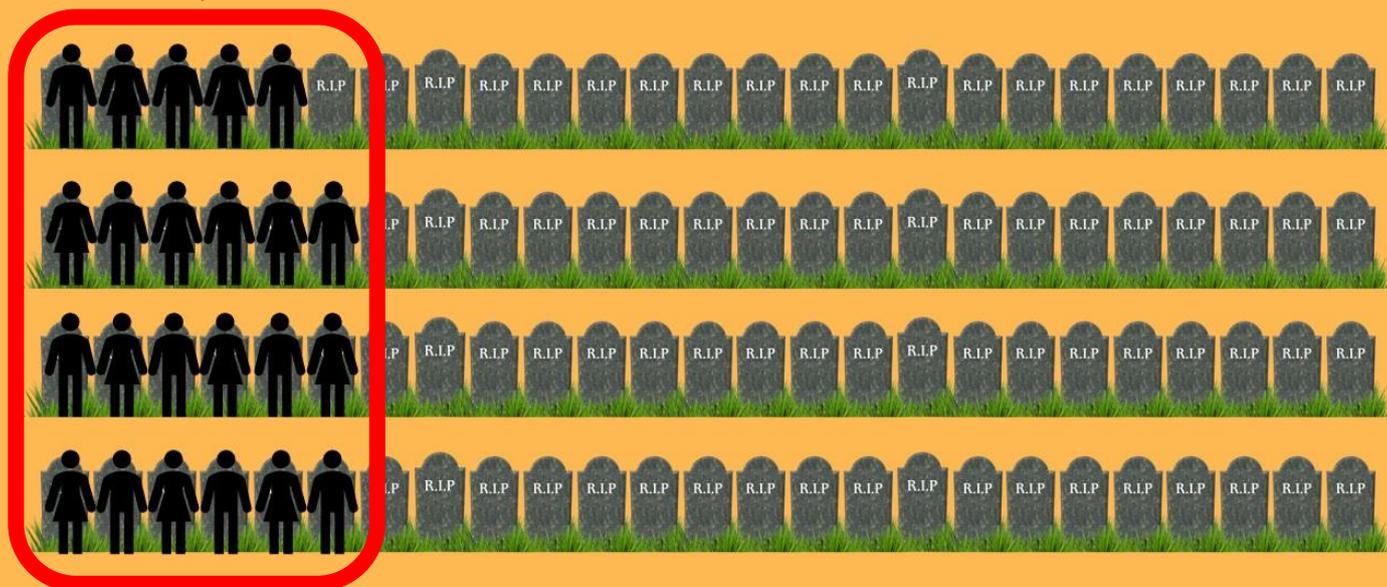
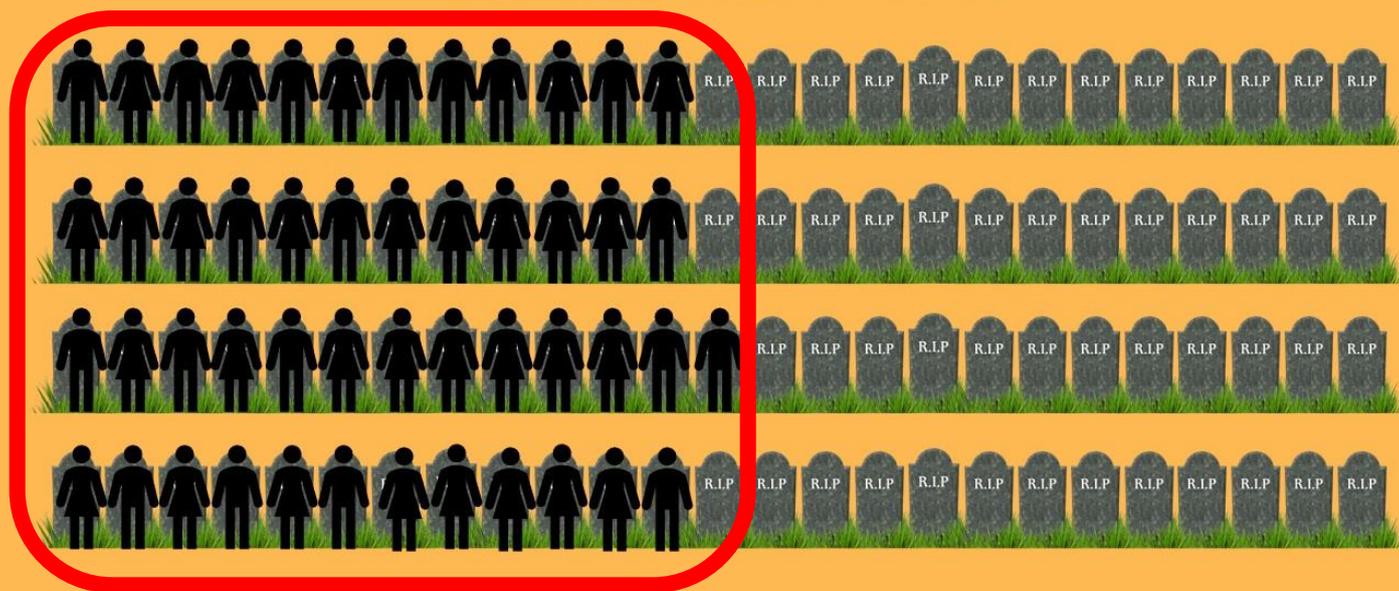
Checking for illnesses

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.



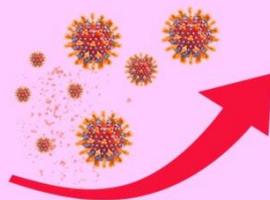
6. The pink part How did COVID affect people with a learning disability?



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

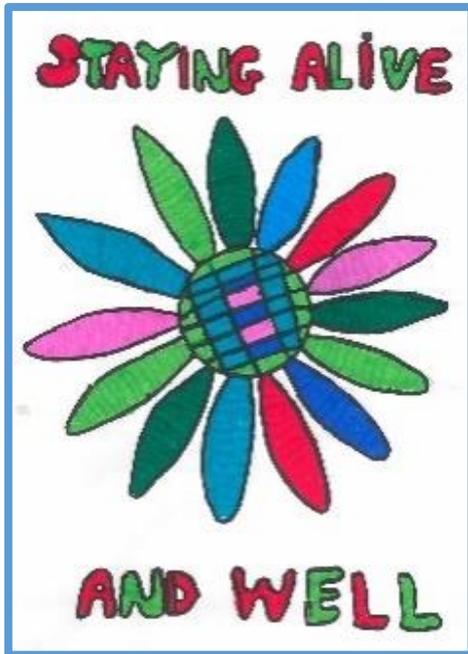


But the number of extra people **with a learning disability** who died, was **double**.

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



The **Covid vaccine** stopped many people dying.



Designed by logo competition winner
Darren Barnes, Greatstone



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:

Richard Keagan-Bull, Maggie Brennan, Amanda Cresswell, Frankie Cutrie, Joanne Kennedy, Andrew Meyer, Lee Scott.

We were supported by:

Irene Tuffrey-Wijne, Jonathon Ding and Natasha Marsland (Kingston University), Christine Koullaburke and David Mahon (Foundation for People with Learning Disabilities), Janice Wycherly (Pathways Associates) and Ruwani Ampegama (Estia Centre).

The **Staying Alive and Well group** is a co-production partnership. They are part of a collaboration led by King's College London, supporting the NHS England & NHS Improvement *Learning Disability and Autism Programme*, including LeDeR.

Contact:

The Staying Alive and Well Group

Address:

c/o Prof I.Tuffrey-Wijne
Kingston University London
Frank Lampl Building
Kingston Hill
Surrey KT2 7LB

Email 1:

I.Tuffrey-Wijne@kingston.ac.uk

Email 2:

leder@kcl.ac.uk