

# LeDeR

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

# 2022

Made with PhotoSymbols™



This report has **7 parts**.

Each part has a **different colour**.





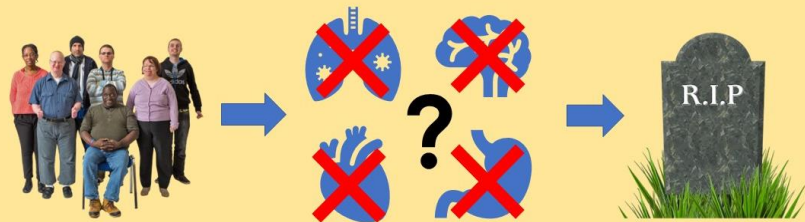
### The grey part:

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**

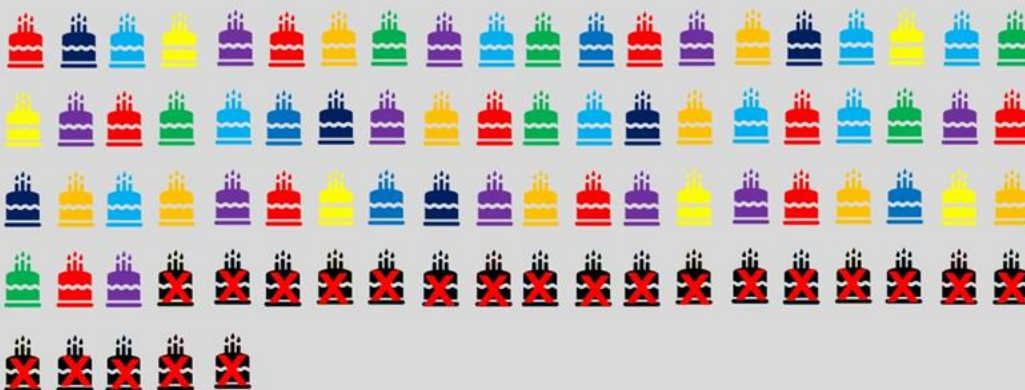


But of each 10 people who **don't have a learning disability**, **9** were still alive at the age of **65**



It means that people who have a learning disability

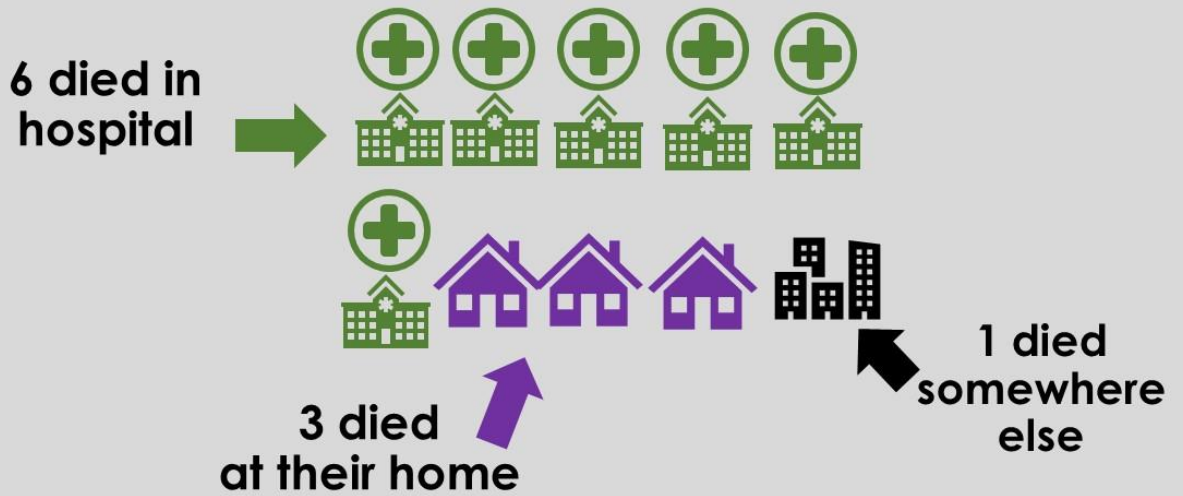
**don't live as long** as people who don't have a learning disability



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...



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



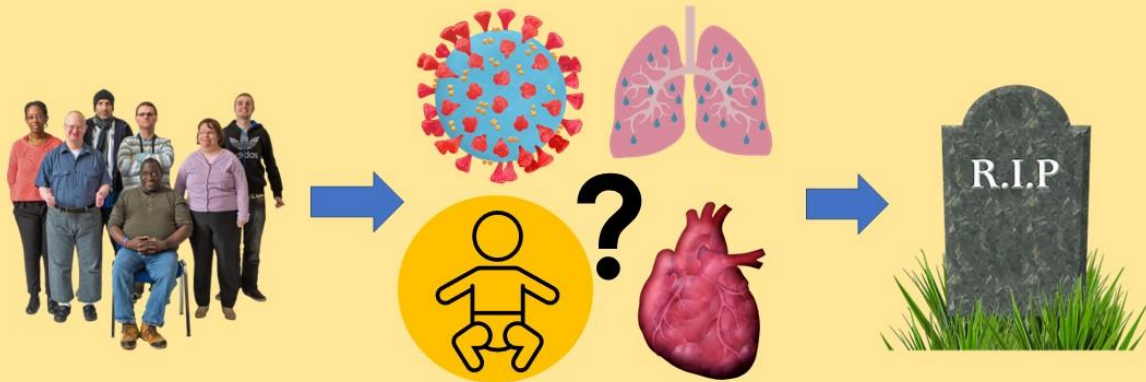
We need to learn more about the people from  
**minority ethnic backgrounds** who died.

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

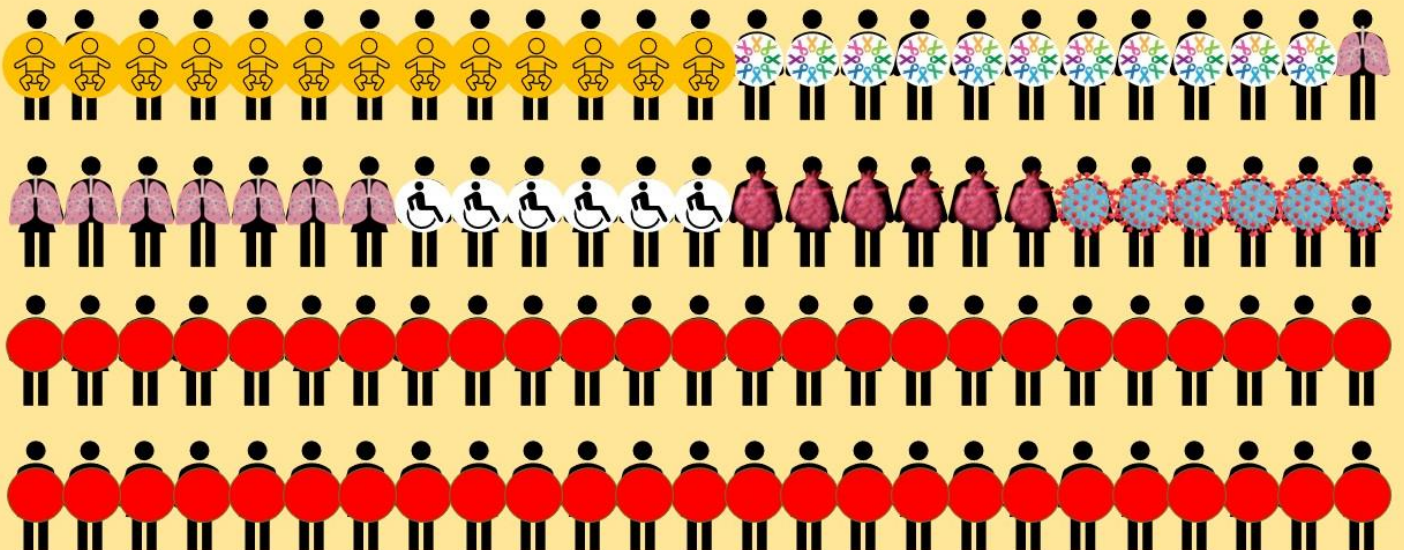




# The yellow part What did people with a learning disability die of in 2022?



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**



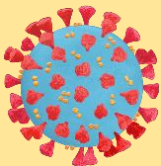
**8** died of **flu** and **lung infections** (pneumonia)



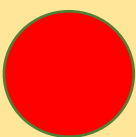
**6** died of **cerebral palsy** and **paralysis**



**6** died of **heart problems**



**6** died of **COVID-19**



**The others** died of **all sorts of other things**





# The blue part

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



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

helped people get good 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



## 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

## The green part:

Which people with a learning disability were more likely to die younger?



### 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?

2022



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



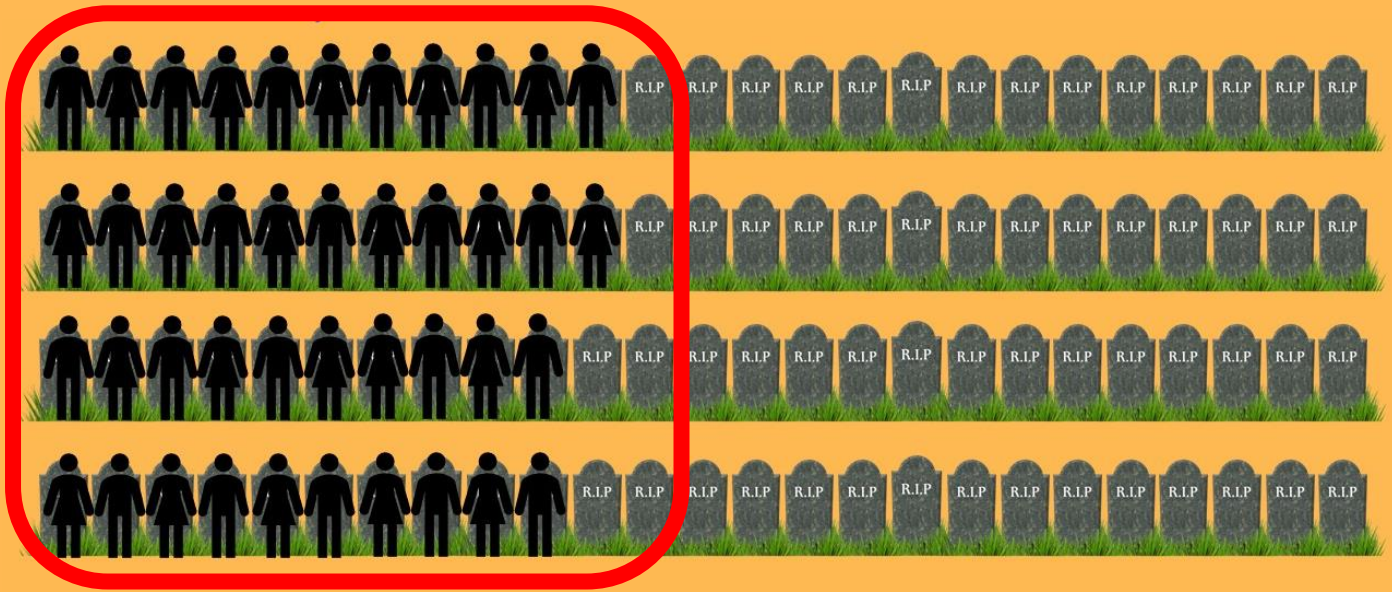
Checking for illnesses

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.





## The pink part: COVID-19 and heatwaves



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**



# The purple part Autistic people without a learning disability



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

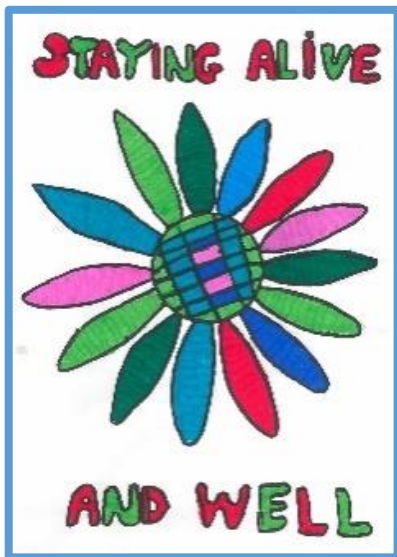
**This is NEW**



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



Designed by logo competition winner  
Darren Barnes, Greatstone



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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](http://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:

Richard Keagan-Bull, Maggie Brennan, Amanda Cresswell, Frankie Cutri, Joanne Kennedy, Wayne McGregor, Andrew Meyer, Caroline Ogundeji, Sonia Reed, Lee Scott, Mark Shackleton, Sunny Sokhal.

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