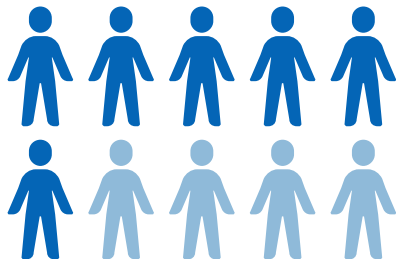


# KEY FINDINGS OF REVIEW OF LIVES AND DEATHS FOR 2022

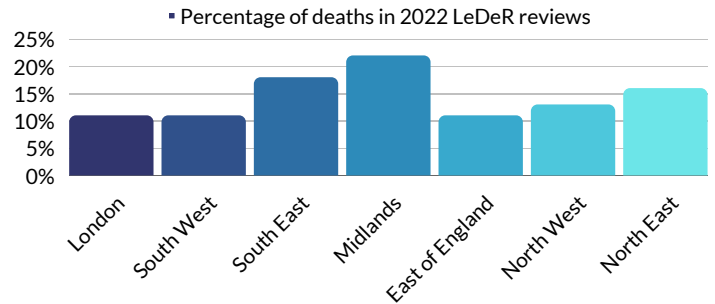
## SEX

**55%** of people with a learning disability who died in 2022 were male.



## REGION

LeDeR reviewed deaths of people with a learning disability from all 7 regions of England.



**94%**

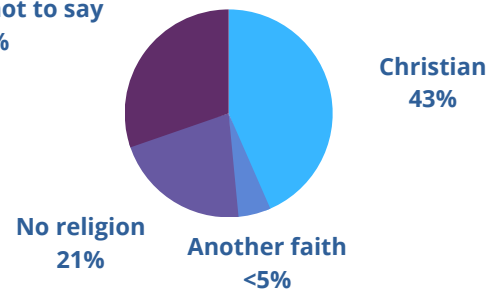
## ETHNICITY

**94%** of people with a learning disability who died in 2022 were denoted as white.

## RELIGION

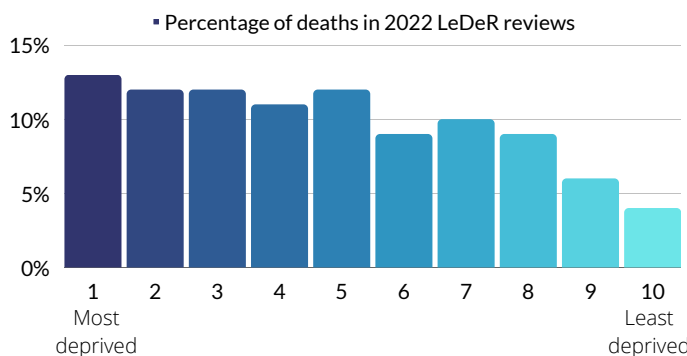
**43%** of people with a learning disability who died in 2022 were denoted as Christian.

Preferred not to say 30%



## DEPRIVATION

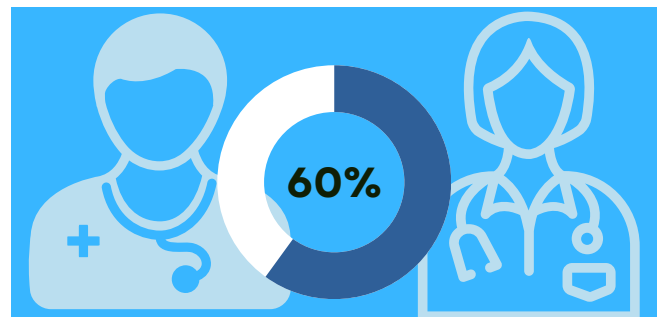
**25%** of people with a learning disability who died in 2022 lived in the most deprived neighbourhoods by decile, compared to **10%** in the least deprived.



**60%**

## NOTIFIERS

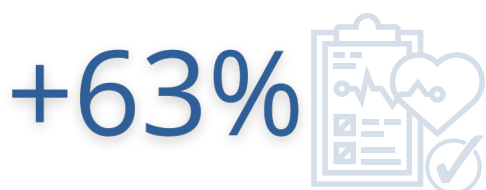
**60%** of people who notified a death to LeDeR in 2022 were health professionals.



# KEY FINDINGS ON CAUSES AND CIRCUMSTANCES OF DEATH

## DNACPR

**74%** of people who died in 2022 had a DNACPR in place at the time of death. Reviewers judged this was correctly followed **63%** of the time. This compares with **61%** of the time in 2021.

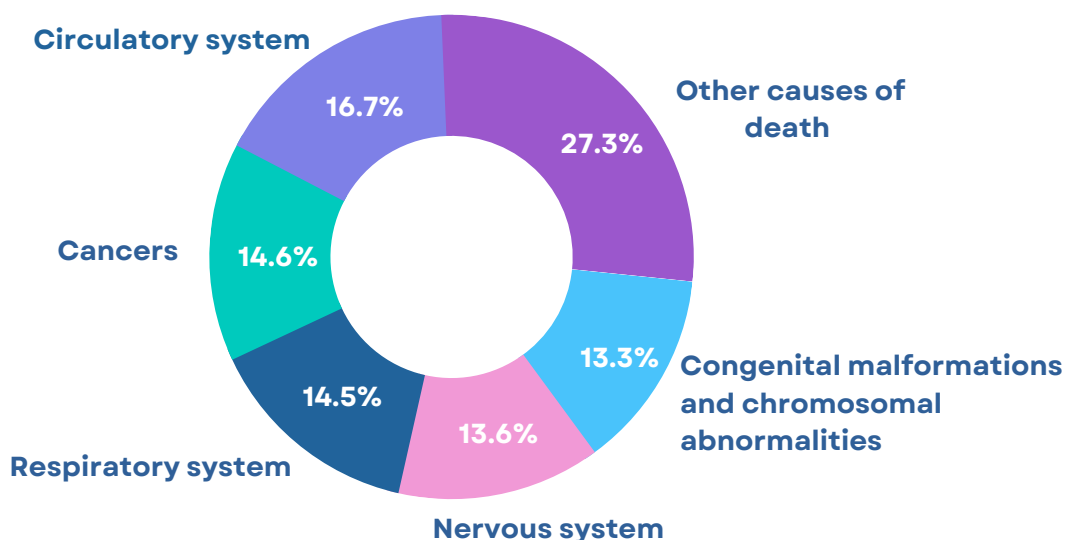


## REFERRALS TO A CORONER

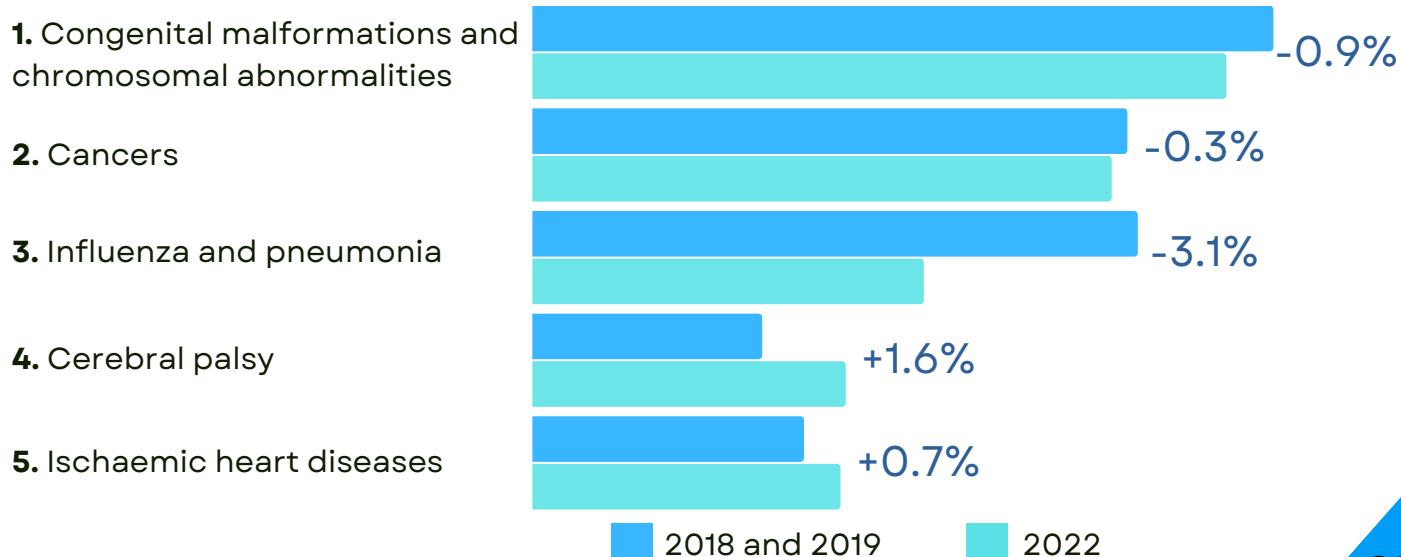
**25%** of deaths that occurred in 2022 were referred to a coroner. This compares to **19%** in 2020 and 2021 and **22%** in 2018 and 2019. **36%** of deaths in the general population were referred to a coroner.



## 5 MOST COMMON CAUSES OF DEATH (ICD-10 CHAPTER)



## 5 MOST COMMON LEADING CAUSES OF DEATH (2022 VS 2018 AND 2019)

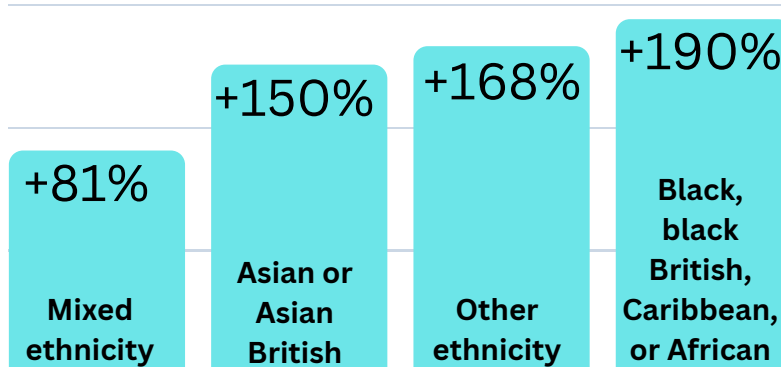


# KEY FINDINGS OF FACTORS ASSOCIATED WITH AGE AT DEATH

## AGE AND ETHNICITY

People from all ethnic minority groups died at a **younger age** in comparison to people of white ethnicity, when adjusting for sex, region of England, deprivation, place of death, and type of accommodation.

% increased risk of dying earlier by ethnic minority group, in comparison with people from white ethnicity backgrounds, when adjusting for other demographic factors



## EPILEPSY AND AGE AT DEATH

**Epilepsy** was the long-term condition that was most **strongly associated with dying at a younger age**. This was followed by deep vein thrombosis, and degenerative diseases.



## CARE AND PREMATURE DEATH

**Appropriate care** was associated with **reductions in premature death**. For instance, care packages that meet a person's needs and have an appropriate use of Deprivation of Liberty safeguards to deliver care are associated with a reduced risk of a premature death.

## AGE AT DEATH

**62.9\* years old** was the median age at death for people with a learning disability in 2022. This is an **increase from 2018**, where the median age at death was 61.8 years. This increase was seen despite the COVID-19 pandemic, showing a continuous improvement between 2018 and 2022.



## TREATMENT AND PREVENTION

The use of **appropriate medical treatment and prevention**, such as the use of vaccines to protect against COVID-19 and pneumococcus and mental health treatments (medications), are associated with **reduction** in the risk of an earlier age at death.



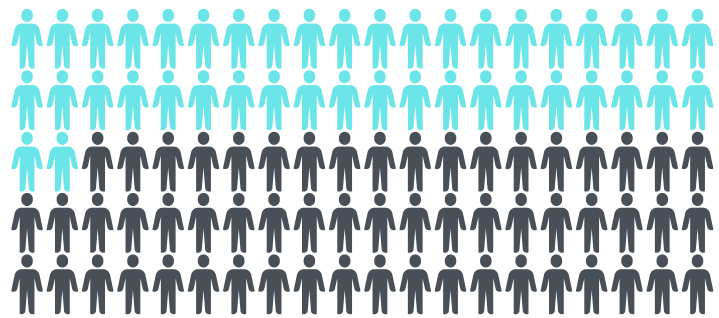
# 62.9 YEARS

\*Calculation based on adult (>18 years old) data only for both 2022 and 2018.

# KEY FINDINGS OF AVOIDABLE MORTALITY

## AVOIDABLE DEATHS

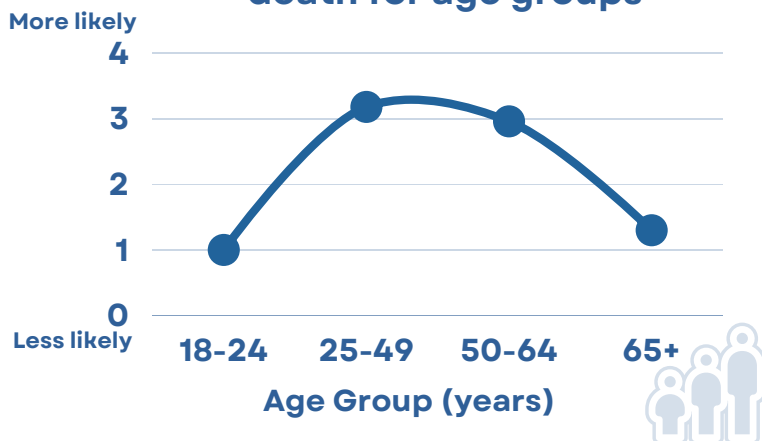
42% of deaths were deemed "avoidable" for people with a learning disability. This is a reduction from 2021 data, which found 50% of adult deaths were avoidable.



This compares to 22% for the general population.

42% of deaths were deemed avoidable

## Odds ratio of avoidable death for age groups



## AGE AND AVOIDABLE DEATHS\*

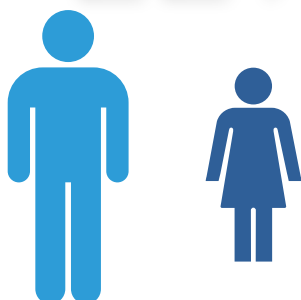
Deaths were more likely to be classified as avoidable with increasing age, peaking in the 25-49 age group before decreasing again for those who died over the age of 65 years.

\*note: deaths of people aged 75+ are defined by the OECD as not being avoidable.

## AVOIDABLE DEATH AND SEX

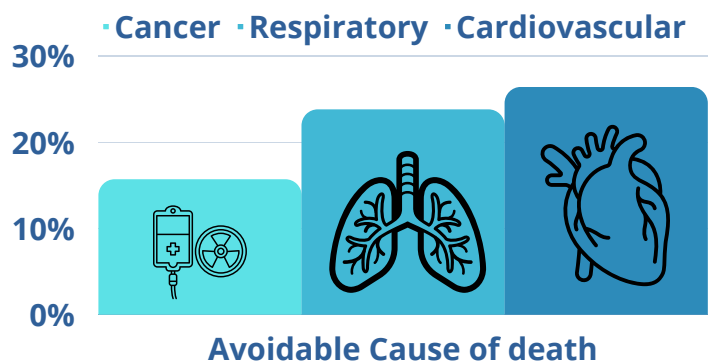
Men were found to be **22% more likely** to die from an avoidable cause of death than women.

+22%



## TOP 3 CAUSES OF AVOIDABLE DEATHS\*\*

26.4% of avoidable deaths were linked to cardiovascular conditions, 23.8% to respiratory conditions (excluding COVID-19), and 15.7% to cancers.



\*\*Unadjusted analyses.

# KEY FINDINGS ABOUT QUALITY OF CARE

## DATA

The findings in this chapter are based on 563 focused reviews of deaths in 2021 and 503 focused reviews of deaths in 2022. We looked at what reviewers said about the quality of care of the person with a learning disability who died.

## CARE PACKAGE

**8 out of 10** of reviewers indicated that the **care package provided met the needs of the individual** in deaths in 2022.



## PROBLEMS WITH CARE

**Organisation systems and processes** were the most commonly reported area of problems with care.



## CONCERNS ABOUT QUALITY OF CARE ARE REDUCING

Concerns with care were expressed in **39%** of deaths which occurred in 2021 and **25%** deaths in 2022



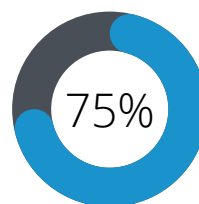
## EVIDENCE OF GOOD PRACTICE



9 out of 10 reviews included evidence of good practice.

## REASONABLE ADJUSTMENTS

Personalised reasonable adjustments were highlighted as crucial tools to support people.



## THE MENTAL CAPACITY ACT

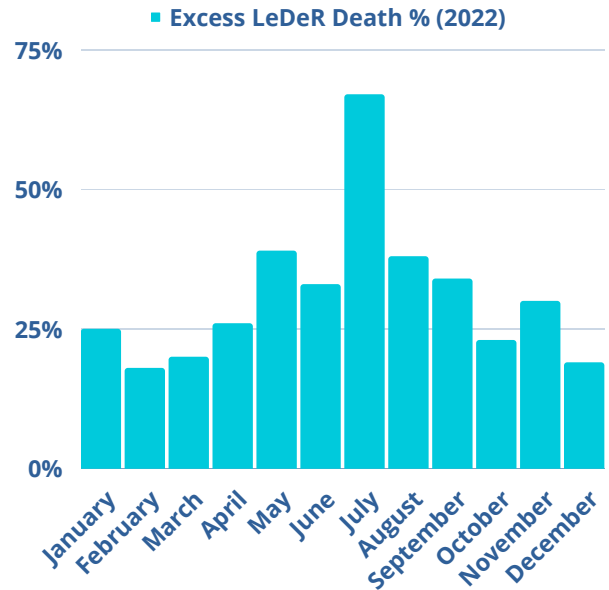
The Mental Capacity Act was correctly followed in three-quarters of deaths in 2022 where it was deemed relevant.

# KEY FINDINGS OF EXCESS DEATHS, COVID-19, AND CLIMATE CHANGE

## EXCESS DEATHS

Deaths notified to LeDeR of occurring in July 2022 appear to be **greater than expected for every month of 2022** when compared to notifications from 2018 and 2019. July 2022 demonstrated the greatest excess.

This may be due to better reporting of deaths, as well as the impact of the pandemic and the heatwave.

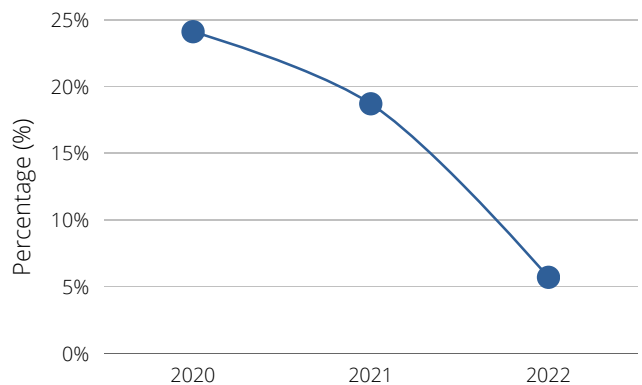


## COVID-19

COVID-19 has **decreased** from 24% of all causes of death in 2020 to 19% in 2021 and **6%** in 2022 for adults with a learning disability. It has gone from the most common cause of death to the 6th most common.



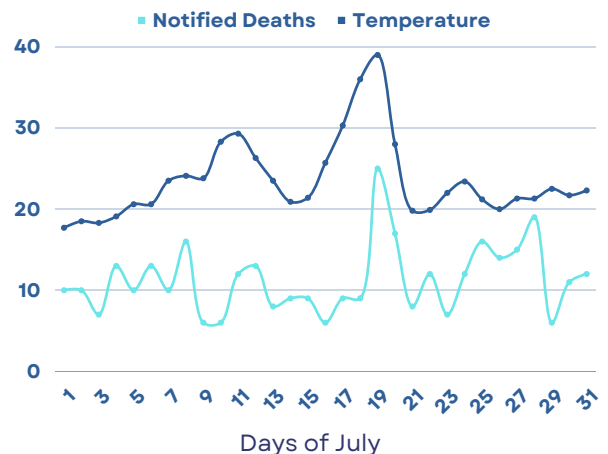
## DEATHS DUE TO COVID-19 ARE FALLING YEAR ON YEAR



## THERE WAS A SPIKE IN NOTIFICATIONS OF DEATHS AROUND THE JULY 2022 HEATWAVE PEAK

July 2022 recorded the highest number of notifications of deaths in 2022, **13% of which occurred on the 19th and 20th of July.**

The 19th of July saw a record high temperature of 40.3°C in England. This spike in deaths was not due to COVID-19 or flu, and appears to be linked to the extreme heat.



# KEY FINDINGS ABOUT AUTISTIC ADULTS WITHOUT A LEARNING DISABILITY IN 2022

## DATA FOR 2022

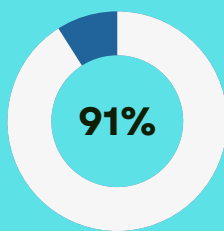
2022 was the first year LeDeR reviewed deaths of autistic adults without a learning disability. The amount of reviews was **small**, with **36 completed reviews**. These reviews are not representative of all autistic adults without a learning disability, and only limited conclusions can be made. Increased reporting is needed to be able to better determine areas for improvement in the care of autistic adults without a learning disability.

# 36 reviews

## THE MOST FREQUENT CAUSES OF DEATH

| Underlying cause of death for autistic adults without a learning disability (grouped ICD-10 codes) | Totals in the data |
|--|--------------------|
| Suicide, misadventure* or accidental death**   | 11                 |
| Respiratory conditions   | 8                  |
| Cardiovascular and stroke related  | <5                 |
| Cancer   | <5                 |
| Other  | 8                  |

Note: \* includes drug and alcohol related deaths that were not thought by the coroner to be intentional.  
\*\* includes falls.

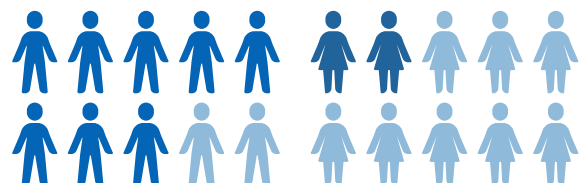


## ETHNICITY

91% of autistic adults without a learning disability were denoted as white.

## SEX

81% of autistic adults without a learning disability who died in 2022 were male, 19% were female\*.



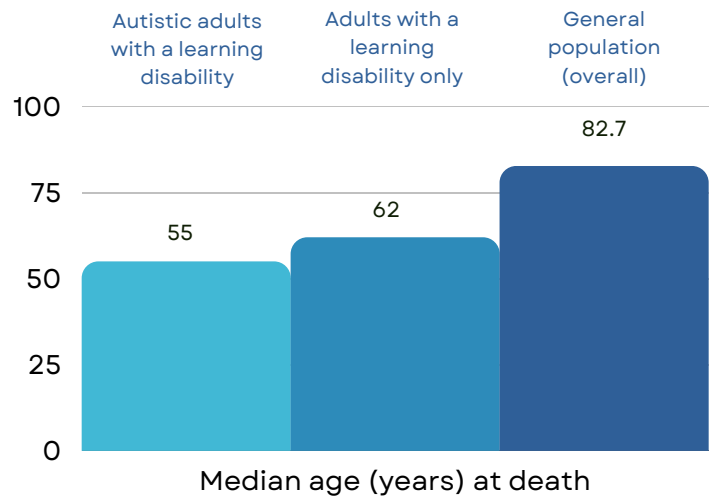
\*a small number (<5) identified as neither male or female, or transgender, but could not be reported in order to ensure de-identified data.

# KEY FINDINGS ABOUT AUTISTIC ADULTS WITH A LEARNING DISABILITY

## AGE AT DEATH

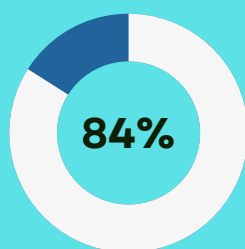
The median age at death for the 178 autistic adults with a learning disability was **55 years**. The median age at death for the general population in 2018-2020 was **82.6 years for males and 86.1 for females**.

# 55 Years



## THE 5 MOST FREQUENT CAUSES OF DEATH (EXCLUDING “OTHER”)

| Underlying cause of death for autistic adults with a learning disability (grouped ICD-10 codes) | Totals in the data |
|---|--------------------|
| Respiratory conditions  | 66                 |
| Cardiovascular conditions   | 27                 |
| Cancer  | 22                 |
| COVID-19  | 17                 |
| Stroke, Cerebral Haemorrhage or Embolism  | 8                  |

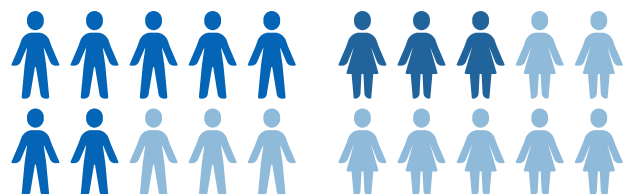


## ETHNICITY

84% of autistic adults with a learning disability and died in 2022 were denoted as white.

## SEX

68% of autistic adults with a learning disability who died in 2022 were male, 30% were female\*.



\*a small number (<5) did not have information regarding their sex available in the data.