



1. Home (<https://www.gov.uk/>)
 2. Coronavirus (COVID-19) (<https://www.gov.uk/coronavirus-taxon>)
 3. COVID-19: deaths of people with learning disabilities
(<https://www.gov.uk/government/publications/covid-19-deaths-of-people-with-learning-disabilities>)
- Public Health
England (<https://www.gov.uk/government/organisations/public-health-england>)

Research and analysis

COVID 19 deaths of people identified as having learning disabilities: summary

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Contents

Aim of the review

Methods

COVID-19 deaths of people with learning disabilities

Factors affecting the risk of COVID-19 death of people with learning disabilities

Deaths in care settings of people with learning disabilities

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This document is an abbreviated plain English version of the summary in the full report.

Aim of the review

The Department of Health and Social Care, with the support of the Chief Medical Officer for England, commissioned Public Health England (PHE) to review the available data on the deaths of people with learning disabilities in England during the coronavirus (COVID-19) pandemic.

The review looked at:

- deaths from COVID-19 of people with learning disabilities
- factors impacting the risk of death from COVID-19 of people with learning disabilities
- deaths in care settings of people with learning disabilities

Methods

The review used 3 main sources of data:

1. The Learning Disabilities Mortality Review (LeDeR) (<http://www.bristol.ac.uk/sps/leder/>) programme.
2. NHS England's COVID-19 Patient Notification System (CPNS) (<https://www.england.nhs.uk/statistics/statistical-work-areas/covid-19-daily-deaths/>), which records deaths in hospitals.
3. Care Quality Commission (CQC) statutory notifications of deaths of people receiving social care (<https://www.cqc.org.uk/guidance-providers/notifications/death-person-using-service-notification-form>).

Where possible, findings are compared to the general population of England.

COVID-19 deaths of people with learning disabilities

PHE used data from the LeDeR and the hospital deaths dataset to establish the number of people with learning disabilities in England who died, definitely or possibly, from COVID-19 from the start of the pandemic to 5 June 2020.

Main findings

LeDeR received 623 reports of deaths, which were definitely or possibly COVID-19 related, among people with learning disabilities between the beginning of February and 5 June. This suggests an estimated national total of 956 deaths, after accounting for under-reporting.

Based on the deaths reported to LeDeR, the COVID-19 death rate for people with learning disabilities was 240 deaths per 100,000 adults with learning disabilities. This is 2.3 times the rate in the general population for the same period. However, after adjusting for under-reporting the estimated rate was 369 per 100,000 adults, which is 3.6 times the rate in the general population.

CPNS, which only records deaths that happen in hospital, recorded 490 deaths of adults with learning disabilities with COVID-19 up to 5 June. This is a rate of 192 deaths per 100,000 adults with learning disabilities, which is 3.1 times the rate for adults without learning disabilities. This is likely to be an underestimate as a quarter of deaths reported in CPNS do not say whether or not the deceased had learning disabilities.

Most deaths (82%) of people with learning disabilities from COVID-19 happened in hospital. This was higher than the proportion of all deaths in previous years (60%) and higher than the proportion of COVID-19 deaths in the general population (63%).

During the peak 3 weeks of the pandemic, the number of deaths from all causes for people with learning disabilities were 3 times the average for the corresponding period in the 2 previous years. For the general population, deaths were twice as high during the same 3-week period, than the 2 years before.

Of the deaths recorded in the CPNS up to 5 June, 1.8% were of people with learning disabilities. GPs in England recognise only 0.57% of adults registered with them as having learning disabilities. So, adults with learning disabilities were over-represented by at least 3.1 times among the numbers of people dying. The disparity was much larger in younger age groups.

Factors affecting the risk of COVID-19 death of people with learning disabilities

COVID-19 has affected different sections of the population to different degrees. In the general population, death rates have been higher for older people, males, people from Black and minority ethnic groups, and people living in areas of greater socioeconomic deprivation.

PHE looked at the impact of these factors on the numbers and rates of death for people with learning disabilities between 21 March and 5 June 2020.

Main findings

Age

COVID-19 deaths among people with learning disabilities were spread more widely across the adult age groups than in the general population. The age bands with the largest number of deaths was 55 to 64 years for people with learning disabilities, but over 75 for the general population. This reflects the pattern of deaths in previous years, and in 2020 from causes other than COVID-19.

COVID-19 increased the number of deaths for people with learning disabilities by a greater margin than for the general population, across all adult age groups.

Age-specific COVID-19 death rates per 100,000 population were higher for people with learning disabilities across all adult age groups, but by a greater margin in younger age groups.

Sex

The age-standardised COVID-19 death rate was higher for men than for women with learning disabilities by 1.4 times in LeDeR notifications and 1.6 times in CPNS hospital death records. This was slightly less than the difference for the general population and for hospital patients without learning disabilities.

Standardising for age and sex, the rate of COVID-19 deaths notified to LeDeR, from 21 March to 5 June, was 451 per 100,000 people with learning disabilities, 4.1 times the rate for the general population. Adjusting this to allow for under-reporting to LeDeR suggests a rate of 692 per 100,000, which is 6.3 times the general population rate.

Ethnic group

Analyses by ethnic group were limited by the small numbers of deaths of people with learning disabilities identified as being from minority ethnic groups. There was also a lack of usable statistics for the numbers of people with learning disabilities from minority ethnic groups in the population.

The proportions of COVID-19 deaths among people with learning disabilities from an Asian or Asian British group, or a Black or Black British group were around 3 times the proportions of deaths from all causes in these groups in the corresponding period of the previous 2 years. They were also greater than the proportions of deaths from other causes in these groups in 2020.

The number of deaths of people with learning disabilities from all causes in 2020 for White groups was 1.9 times the number in the 2 previous years. For Asian or Asian British groups it was 4.5 times and for Black or Black British groups it was 4.4 times.

Regions of the country

The number of deaths from all causes for people with learning disabilities rose by 3.7 times in London, compared with the previous 2 years, but by only 1.6 times in the South West. Other regions were somewhere between these increases.

The data available was not adequate to support more detailed analysis on area level social deprivation.

Deaths in care settings of people with learning disabilities

Residential social care settings have a potential risk of transmitting respiratory viruses because of the frequent contact between staff and the people they are caring for.

This review looked at the extent to which people with learning disabilities appear to have been at additional risk from COVID-19 due to the types of social care they receive.

Death rates in care settings were estimated from numbers of notifications to the CQC and numbers reported as receiving social care in annual social care statistics. This CQC data covered a shorter period, from 10 April to 15 May 2020.

Main findings

COVID-19 accounted for 54% of deaths of adults with learning disabilities in residential care in the review period, slightly less than for people with learning disabilities generally, but still much more than in the general population.

The rate of COVID-19 deaths for adults with learning disabilities in residential care was higher than the rates of COVID-19 deaths of adults with learning disabilities generally, estimated from LeDeR. It was 2.3 times the rate calculated from actual LeDeR notifications and 1.5 times the estimated rate adjusting for under-notification. This difference is likely in part to reflect the greater age and disability in people in residential care.

PHE data on the number of outbreaks in care homes (<https://www.gov.uk/government/statistical-data-sets/covid-19-number-of-outbreaks-in-care-homes-management-information>) indicates that care homes looking after people with learning disabilities were less likely than other care homes to have had COVID-19 outbreaks. This is likely to be related to the fact they have fewer bed spaces.

COVID-19 accounted for 53% of deaths of adults with learning disabilities receiving community-based social care. It's hard to comment on the scale of deaths in community social care because the numbers of people receiving care from providers which are likely to report their deaths is not clear. This level of additional mortality is similar to the level in residential care.

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