



The Learning Disabilities Mortality Review
(LeDeR) Programme



Annual Report 2020

Easy Read

University of
Bristol Norah
Fry Centre
for Disability
Studies



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LeDeR programme Annual Report 2020

Easy read version

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Some difficult words we use.

Average age	To work out the average age, we add up all the ages of everyone who has died. Then we divide that number by the number of people who have died.
Antidepressant medication	Medicine given to someone with mental health problems, usually people who are depressed.
Antipsychotic medication	Medicine given to someone with mental health problems, usually people who see or hear things that might not be there. It is sometimes given when a person has behaviour that is difficult for the people who support them.
Aspiration pneumonia	An infection in your lungs caused by food or fluids going down 'the wrong way'.
Child Death review	The national system that checks up on the deaths of all children.
Circulatory system	The parts of the body to do with the heart and tubes that carry blood.
Coroner	An official who looks into why someone died.
COVID-19	A virus that spread across the world in 2020, causing a lot of people to die.
Criminal justice system	The courts, the police or the prison service.
DNACPR decision	If doctors think a person's heart would not be able to be restarted if it stops, they make a Do Not Attempt Cardiopulmonary Resuscitation decision.
Fever	A high body temperature. It usually means that someone is unwell.
Long-term health conditions	Health conditions that do not go away. A person would always have the condition.
NHS111	A phone line that provides advice about illnesses or what to do if a person is unwell.
Pneumonia	An infection in the lungs caused by 'bugs' called bacteria.
Respiratory system	The parts of the body to do with breathing.
Secure mental health services	Services for people with mental health needs that do not allow the person to go out when they want.
Shielding	Staying away from people to try and avoid catching the COVID-19 virus.
Symptoms	Changes in the body that are noticed when a person is ill.

Introduction



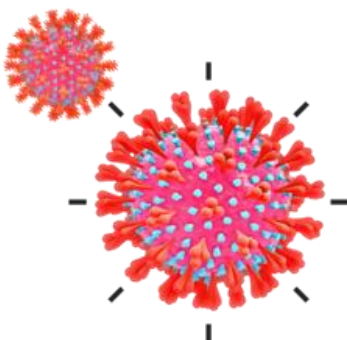
It is now 5 years since the LeDeR programme was set up



In this report we look at look at the deaths of people who died in 2018, 2019 and 2020.



We want to see if things have got any better for people with learning disabilities in this time.



2020 was an unusual year because of the COVID-19 virus. So, we need to be careful comparing how things were in 2020 with the other years.

Chapter 1. How many people died

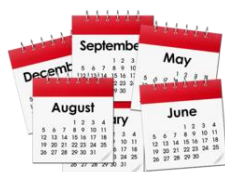


This report looks at the deaths of 9,110 people with learning disabilities.



They all died between 1st January 2018 and 31st December 2020.

8,488 of these people were adults.
622 were children.



About 200-300 people with learning disabilities die each month.

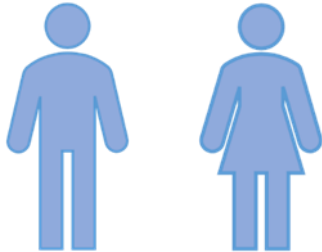


The number of deaths is a little higher in the winter.



In 2020, there were more deaths than usual in March, April and May because of COVID-19.

Chapter 2. About the people who died



Gender

From 2018 to 2020, **57 in every 100** people who died were male.

43 in every 100 people who died were female. Fewer than 10 people were described as not male or female.



Ethnicity

From 2018 to 2020, most adults were white British- **92 in every 100**.

Fewer children were white British – **57 in every 100**



Level of learning disabilities

From 2018 to 2020, most **adults** had mild or moderate learning disabilities – **65 in every 100**.



We don't have much data about the level of learning disabilities for children.

The data we have suggests that lots **more children had profound and multiple learning disabilities** than adults.



Age at death

The average age at death has increased by 1 year between 2018 and 2020 for males and females. In 2020 it was 61 years.

That means that of the people with learning disabilities who died in 2020, half died before age 61 and half died after age 61.



From 2018 to 2019, men with learning disabilities died, on average 23 years sooner than men in the general population.



Women with learning disabilities died, on average, 27 years sooner.



Adults who died the youngest were men from minority ethnic groups with severe, profound and multiple learning disabilities.

Chapter 3. Things that influenced how old a person was when they died



There are lots of things that can affect how old a person is when they die, such as:

- How much money they have.
- How healthy their lifestyle is.
- Whether they have access to good health and care services.



We looked at some of the things that might influence how old people were when they died.

We will look at what these are first, then will look at if they were related to how old a person was when they died.



Long-term health conditions

From 2018-2020, almost half of adults (**46 in every 100**) who died had 7 to 10 long-term health conditions or additional health needs.



The place where people usually lived
From 2018-2020 of the people who died:

- 30 people in every 100 had usually lived in a residential care home.
- 29 people in every 100 had lived in supported living.
- 25 people in every 100 lived in their own or their family home.
- 15 people in every 100 lived in a nursing home.



People who were the most likely to live in their own or their family home were:

- People in the youngest age groups.
- People with profound and multiple learning disabilities.
- People from minority ethnic groups.



People who were the most likely to live in a residential home or a nursing home were:

- People in the oldest age groups.



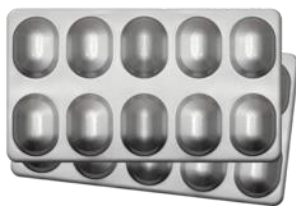
If people lived a long way from their home area

A small number of people (**about 7 in every 100**) had been living a long way from their home area when they died. We sometimes call this being in an 'out-of-area placement'.



Who people received their main support from

Most people (**83 in every 100**) had received their main form of support from a paid carer.



Medications usually prescribed for a person

Most people (**98 in every 100**) had been prescribed one or more usual medications.

24 in every 100 people were usually prescribed an antipsychotic medication.

28 in every 100 people were usually prescribed an antidepressant medication.



Annual health checks

Three-quarters of people (**74 in every 100**) had had an annual health check in the year before they died.



So, who is most likely to die at a young age?

We looked at who was most likely to die at age 18-49 years.



People most likely to die at this age early were:

- People of Asian ethnicity.
- People from Black ethnic groups.
- People from mixed or more than two ethnicities.



- People with severe learning disabilities.
- People with profound and multiple learning disabilities.



- People who had had their freedom taken away by the Criminal Justice System or by being in secure mental health services.



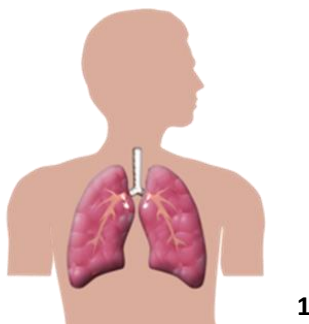
- People who had not had an annual health check in the past year.

Chapter 4. Causes of death

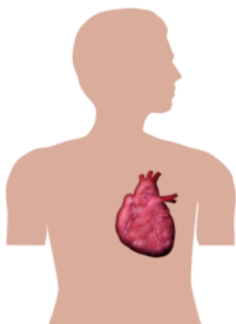


The main medical causes of death have been similar between 2018 and 2020. These were:

- Problems with the respiratory (breathing) system.
- Problems with the circulatory (heart) system.
- Health conditions that a person is born with.



The proportion of people with learning disabilities who died from problems with the respiratory (breathing) system was more than people in the general population.



The proportion of people with learning disabilities who died from problems with the circulatory (heart) system was less than people in the general population.

¹ We have used blue arrows to show whether the findings for people with learning disabilities were greater or less than in people in the general population.



The proportion of people with learning disabilities who died from problems they were born with was more than people in the general population.

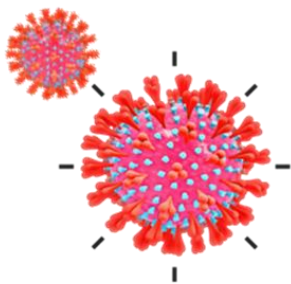
In both 2018 and 2019, the health conditions most frequently put on a person's official cause of death form were:



- Infection in the lungs (pneumonia) caused by germs.



- Pneumonia caused by food or drink going down the wrong way (this is called aspiration pneumonia).



In 2020, the health condition most frequently reported on a person's official cause of death form were:

- COVID-19.
- Infection in the lungs (pneumonia) caused by germs.
- Pneumonia caused by food or drink going down the wrong way.



There were fewer avoidable medical causes of death in adults and children with learning disabilities between 2018 and 2020.

More adults and children with learning disabilities die from avoidable medical causes of death than people in the general population.

Chapter 5. Some of the things that happened when a person died



In this chapter we look at some of the things that happened when people died.



The place where people died

About **60 in every 100** people with learning disabilities died in hospital.

In the general population of England, 46 in every 100 people die in hospital.



**DO NOT
RESUSCITATE**

Decisions about restarting a person's heart if it stops

Sometimes a decision is made not to try and restart a person's heart if it stops. We call this a DNACPR decision. That stands for Do Not Attempt Cardiopulmonary Resuscitation.

For about **71 in every 100** people a decision had been made that doctors would not try and restart their heart if it stopped.



The people most likely to have a DNACPR decision were:

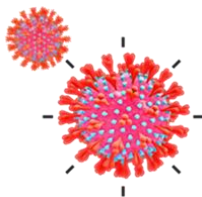
- People living in a nursing home.



- People in the oldest age groups.



- People with moderate, severe, profound and multiple learning disabilities.



- People who had COVID-19 in 2020.

A small number of reviewers thought that a DNACPR decision had not been made correctly. There were three main reasons for this:



1. The way in which the decision had been made was wrong – it often had not involved the person themselves or their family or those who knew them well.



2. There were problems with the paperwork – sometimes parts of the form had been left out or it hadn't been signed.



3. Sometimes the reason given not to try and restart the person's heart was because they had learning disabilities or Down's syndrome.



If the person's death was reported to a coroner

A coroner is an official who looks into why someone died.



A smaller proportion of people with learning disabilities had their death reported to a coroner compared to people in the general population.



We looked at what had happened when children with learning disabilities had died.

The Child Death Review form tells us about possible things that might have been linked to a child's death.



For most deaths of children, the child death reports noted that it was something about the child that was linked to their death.

Of these, **24 in every 100** said that having 'learning disabilities' was linked to the child's cause of death.



11 in every 100 child death reports noted that something could have been done to avoid the child dying.

Lots of reasons were given, including:

- The quality of care given to the child.



- Things to help people become healthier, such as stopping the child's parents from smoking.



- Making sure that early signs that a child was ill were responded to.



- Children born to family members who were related, such as cousins who had married.

Chapter 6. The quality of care a person received



In this chapter we look at what reviewers said about the quality of care given to people with learning disabilities.

For people who had died in 2020, compared to people who had died in 2018 or 2019:



- Reviewers gave more examples of good quality care.
- Reviewers reported that there were fewer times where there had been problems with a person's care.



For deaths in 2020, **71 in every 100** reviewers gave one or more examples of what they thought was good quality care. They said that this was when:



- Everyone worked well together to support the person.



- The care provided was what was needed by the person – we call this person-centred care.



- Everyone tried to think ahead about what the person might need in the future, as well as what they needed at the present time.



For deaths in 2020, **14 in every 100** reviewers said that there had been problems with the ways that different organisations did things.

This is better than in 2018 and 2019.

These problems were mostly because services were not working together to support a person.



For deaths in 2020, **12 in every 100** reviewers said that there had been delays in the person's care and treatment.

This is better than in 2018 and 2019. The delays were mostly about finding out what was wrong with the person and treating them.



For deaths in 2020, **10 in every 100** reviewers said that concerns had been raised about the person's death.

Most concerns were raised by the family members of the person who died.



The concerns were mostly about:

- The quality of care provided to the person.
- Delays in finding out what was wrong with the person and treating them.





For deaths in 2020, **6 in every 100** reviewers said that there had been gaps in services that may have contributed to the person's death.

The gaps were mostly because of:

- The availability of staff
- The skills and knowledge of staff working in general health settings like hospitals and GP surgeries.



At the end of their review, reviewers have to think about everything they have found out and give a grade for the quality of care.



For people who died in 2020, reviewers thought that **58 in every 100** people had received care that met good practice or was even better than this.



This is good, but it still means that **42 in every 100** people who died in 2020 didn't receive care that met good practice standards.



We looked at whether some people were more likely than others to receive the poorest quality of care. We did not find any clear pattern to this.

Chapter 7. Deaths of people from minority ethnic groups



In this chapter we look at what we know about the deaths of people from minority ethnic groups.



Not as many adults from minority ethnic groups as we would expect had their deaths reported to the LeDeR programme.

8 in every 100 deaths reported to LeDeR were of people from minority ethnic groups.

In the general population, **15 in every 100** people are from minority ethnic groups.

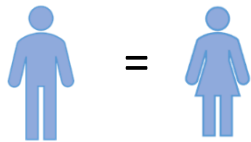


There was a big difference in the number of deaths of adults and children with learning disabilities from minority ethnic groups.

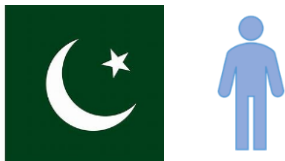


6 in every 100 deaths of adults were people from minority ethnic groups.

37 in every 100 deaths of children were people from minority ethnic groups.



The proportion of males and females was similar in different ethnic groups.



The only group that was different was people from Pakistani ethnicity where more adults were male.



Information about the level of learning disability is not available for many children, so we have not been able to look at this by ethnicity.



In adults, more people with mild or moderate learning disabilities were white British (**67 in every 100** people) than Asian (**41 in every 100** people).



In adults, more people with profound and multiple learning disabilities were Asian (**21 in every 100** people) than white British (**7 in every 100** people).

There are big differences in the age at death by ethnicity.



Not many children who died were white British (**4 in every 100** children).

More children who died were from mixed or more than two ethnic groups (**32 in every 100** children) or from Asian ethnic groups (**31 in every 100** children).



More adults who died aged 65 and over were white British (**42 in every 100** adults).

Not many adults who died aged 65 or over were from Black/African/Caribbean ethnic groups (5 in every 100 adults) or from Asian ethnic groups (**7 in every 100** adults).



More people who lived in their own or the family home were from Asian ethnic groups (**67 in every 100** people).

Fewer people who lived in their own or the family home were white British (**23 in every 100** people).



More white British people were living in supported living or residential care settings than people from other ethnic groups.



Reviewers thought that for most people, the care that the person received was what they had needed.

People whose care had not met their needs quite as well were people from mixed or more than two ethnic groups.



More people who died in hospital were from Asian ethnic groups (**68 in every 100** people).

Smaller proportions of people from other ethnic groups died in hospital.



There was no difference between different ethnic groups about whether a decision had been made to restart a person's heart if it stopped.



Adults and children in all minority ethnic groups had their deaths reported to a coroner more frequently than white British people.



People from different ethnic groups died from similar causes of death.

Bacterial pneumonia was the most common cause of death in people from each of the ethnic groups.



There was no difference between different ethnic groups in the proportion of people who died from medical conditions that could be prevented, such as winter flu or accidents.

There is a difference when looking at people who died from medical conditions that could be treated.

More people from Black/African/Caribbean ethnic groups died from causes of death that could have been treated (**44 in every 100** people).



More people from mixed or more than two ethnic groups also died from causes of death that could have been treated (**43 in every 100** people).

Not so many people from Asian ethnic groups died from causes of death that could have been treated (**36 in every 100** people).

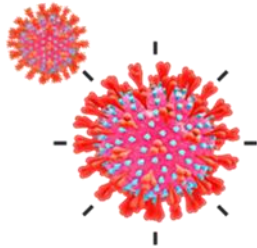
Reviewers reported that more adults from minority ethnic groups had problems with their care than did white British people.



The biggest difference was when reviewers noted if anyone had been concerned about a person's death.

- More deaths of people from mixed or more than two ethnic groups had concerns raised about their care (**23 in every 100** adults).
- Fewer deaths of white British people had concerns raised about their care (**10 in every 100** adults).

Chapter 8. Deaths of people from COVID-19



In 2020 we wrote a report about 206 adults with learning disabilities who were thought to have died from COVID-19.



In this chapter we look at the deaths of 718 adults who died from COVID-19 in 2020.



Each of them had COVID-19 written in the official records of their cause of death.

Of the 718 people, 476 have had the review of their death completed.

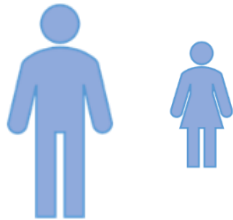


A bigger proportion of people with learning disabilities died from COVID-19 than people in the general population.



In people with learning disabilities, **24 in every 100** people died from COVID-19 in 2020.

In the general population, **13 in every 100** people died from COVID-19 in 2020.



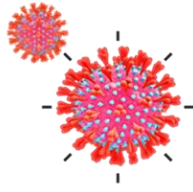
A bigger proportion of males with learning disabilities died from COVID-19 than did females.



People with learning disabilities who died from COVID-19 were younger than people in the general population who died from COVID-19.

4 in every 100 people with learning disabilities who died from COVID-19 were aged 85 or over.

42 in every 100 people in the general population who died from COVID-19 were aged 85 or over.



People who died from COVID-19 were *more* likely than people who died from other causes to:



- Be from Asian ethnic groups.



- Live in places that were not their own home or the family home.



- Have Down's syndrome.



- Be obese (very over-weight).



Autistic people were *no* more likely to die from COVID-19 than other people.



Not many reviewers were able to find out whether the person had been 'shielding' from COVID-19 or where they may have caught the virus from.

Lots of people who have COVID-19 have the same problems – we call these 'symptoms' of having the illness.



NHS England advises that the main symptoms of the illness are:

- A cough.
- A fever (high body temperature).
- Not being able to smell or taste things.



The symptoms that most people with learning disabilities had were:

- A cough (**52 in every 100** people with COVID-19 had this).





- A fever (**51 in every 100** people had this).



- Difficulty breathing (**37 in every 100** people had this).



No one was said to have been unable to smell or taste anything.



A bigger proportion of people with learning disabilities who had COVID-19 died in hospital than did people in the general population.



Almost three-quarters of reviewers of people who died from COVID-19, noted some best practice how the person was supported.

The examples of best practice were:



- Thinking about what the person needed and services meeting their needs.



- Joined-up' working with good communication between services supporting the person.



- The involvement of families.



- Support being able to change as the person's health changed.



Some people had difficulty getting the right healthcare for someone with COVID-19.

The most common problems were:



- Getting tests to see if a person had COVID-19 or not.



- Getting support from specialist learning disability services.



- Receiving a good service from NHS111.



Other problems were with how the services providing support worked.

These problems included:



- The arrangements in hospitals for COVID-testing and protecting patients from catching the virus.



- Services not making reasonable adjustments for people with learning disabilities.



- Confusion about national guidance about protecting people from COVID-19.



A small number of people said they had concerns about the care provided to a person who died from COVID-19.

The concerns were mainly about:



- The medical or nursing care.



- Arrangements for sending someone home from hospital.



- Not stopping COVID-19 from spreading.



Not recognising signs that a person's health was becoming worse.



Chapter 9. Summary and what we think should change



The care of some people with learning disabilities improved between 2018 and 2019.



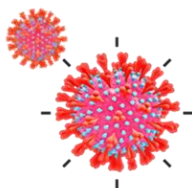
This was not the case for all people with learning disabilities.



People from minority ethnic groups died younger than white British people. They also died from treatable causes of death more often.



People with learning disabilities died from COVID-19 more frequently than people in the general population.



The COVID-19 pandemic has highlighted the impact of health inequalities in the provision of care of people with learning disabilities.

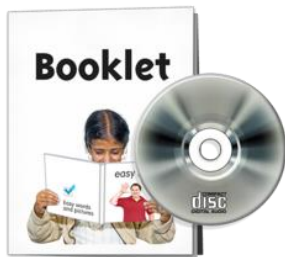
We have suggested 10 things to improve the lives of people with learning disabilities.



1. LeDeR reviews to pay more attention to the inequalities faced by people from minority ethnic groups.



2. The new Integrated Care Systems must pay attention to the needs of children and adults from minority ethnic groups living in their local area. They need to make sure that they provide the services that people need.



3. A national information pack is needed that tells people with learning disabilities and their families about:

- Their legal rights.
- National services and how to access them.
- Local sources of support.



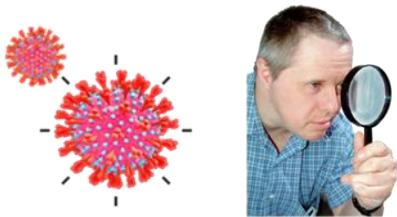
Local areas need to make sure that this is available to people from minority ethnic groups and that they understand it.



4. There needs to be better partnership-working with local communities, particularly minority ethnic communities.



5. Local areas must develop long-term plans that show how they will meet the needs of people with learning disabilities that the COVID-19 pandemic has shown are a problem.



6. From the start of any future public health emergency, such as COVID-19, the needs of people with learning disabilities must be considered.



7. NHS111 services must provide training to NHS111 staff about how to respond appropriately to calls about people with learning disabilities or from people with learning disabilities and their families.



8. A LeDeR representative should always be invited to the child death review meeting for children with learning disabilities.



9. More information is needed about people who have recently been under mental health or criminal justice restrictions.

This information should be used to provide better services for people.



10. Our previous recommendations about minimising the risk of aspiration pneumonia in people with learning disabilities need to be acted upon and this information shared.

Thank you



There are lots of people to thank.

Thank you to the people with learning disabilities and family members who talked with us about what we had found out. They helped us with ideas for how to improve things for people with learning disabilities:

Pam Bebbington

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Dawn Wiltshire

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