



The Learning Disabilities Mortality Review  
(LeDeR) Programme



# Deaths of people with learning disabilities from COVID-19

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## Deaths of adults with learning disabilities from COVID-19: a comparator analysis of 206 deaths

In July 2020, the Learning Disabilities Mortality Review (LeDeR) programme published a short report describing key information relating to the first 50 completed LeDeR reviews of deaths of people with learning disabilities whose deaths had been attributed to COVID-19<sup>1</sup>.

This report builds on that previous report, by describing the circumstances leading to death for a representative sample of 206 adults with learning disabilities. The majority (79%) of their deaths were attributable to COVID-19; a small group whose deaths were due to other causes are included as a comparator group. The selection criteria for inclusion in this sample is described in Appendix 1.

The aim of this report is to highlight those aspects of the condition itself, or the care provided to those who have died, that can inform a better understanding of COVID-19 as relevant to people with learning disabilities. The objectives are to:

- Describe the symptoms and presentation of COVID-19 in a sample of people with learning disabilities.
- Describe the circumstances of their death.
- Extract any learning for future service provision in relation to COVID-19 in people with learning disabilities.

### Some of the people who have died

Yvonne<sup>2</sup> was in her 50s when she died from COVID-19. Yvonne was described as being exceptionally sociable and would spend time in her local community where she was very popular. Yvonne had always loved to read and enjoyed the local library. She would rarely be seen without a book and enjoyed reading all genres and topics. She lived with her family until her parents passed away. She then lived in supported living accommodation so that she could be as independent as possible – this was how she liked to live.

Norman was in his late 70s when he died from COVID-19. Norman was described as being happy, easy going and liked to communicate with others. He loved birds and it was very important to him that he had a bedroom where he was able to look out at wildlife. He had kept birds as pets throughout his life. Though he was not able to live independently, he liked his own space and would watch TV alone in his room sometimes.

Hannah was in her late teens when she died from COVID-19. When Hannah was happy, she would laugh out loud. It was difficult for others to know when Hannah was not happy, but her family could sense this and could tell by the gestures that she would make. Hannah enjoyed going to school and loved the sensory room and the massages she would have there. Hannah lived with her mum and her older brother.

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<sup>1</sup> <http://www.bristol.ac.uk/sps/leder/news/2020/leder-covid-19-reviews.html>

<sup>2</sup> All names throughout this report have been changed to protect confidentiality.

## Summary and key findings

This report describes the circumstances leading to death for a representative sample of 206 adults with learning disabilities.

The majority of the 206 deaths (79%, n=163) were attributable to COVID-19: 27% of the total number of COVID-19 deaths notified to the LeDeR programme from 2<sup>nd</sup> March 2020 – 9<sup>th</sup> June 2020. Forty-three (21%) of the 206 deaths were attributed to other causes and are included as a comparator group – 6% of the total deaths from other causes occurring during this period.

Key findings are as follows.

1. There is a striking difference in age at death between COVID-19 deaths in the general population compared with people with learning disabilities. In the general population of England and Wales, 47% of deaths from COVID-19 were in people aged 85 years and over. Of all deaths of people with learning disabilities from COVID-19 notified to the LeDeR programme, just 4% were aged 85 years and over. This is likely to be influenced by the lower median age at death in people with learning disabilities than in the general population but indicates that were age thresholds to be introduced for shielding people from COVID-19, they would be likely to disproportionately disadvantage people with learning disabilities.
2. A third (35%) of those who died from COVID-19 lived in residential care homes, rising to almost half of those with Down's syndrome. A quarter (25%) lived in supported living settings. Priority must be given to supporting measures to prevent the spread of COVID-19 in these settings.
3. People who died from COVID-19 were more frequently reported to have respiratory conditions (72%), compared to those who died from other conditions (60%). Other long-term health conditions more frequently reported in people who died from COVID-19 compared to people who died from other causes were hypertension (33% compared to 21%) and obesity (33% compared to 21%). The differences, whilst not statistically significant, may suggest that targeting these conditions with specific public health and preventative measures for people with learning disabilities would appear to be appropriate.
4. Reviewers reported that 16 of those who died from COVID-19 had received a letter instructing them to shield. Eleven people who died from COVID-19 had not received a letter instructing them to shield, but had, nevertheless, been protected as if shielding. Twenty of these 27 people lived in a setting with external paid carers - seven lived in a nursing home, seven in a residential care home and six in supported living settings. Indeed, of 79 people who died from confirmed or suspected COVID-19 and for whom the likely source of infection was available, half were thought to have caught the infection from other residents or staff in their care home. This suggests a need to improve preventative measures in these particular settings.
5. Of those who died from COVID-19, 37% had all three symptoms of cough, fever or difficulty breathing; 39% had two of the symptoms and 21% had one of these symptoms. No one reported a loss of sense of smell or taste, suggesting that this symptom is more difficult to identify in people with learning disabilities than in the general population so should not be relied on. Lethargy and tiredness were more frequently reported in people who died from COVID-19 (39%) compared with other causes (23%), so greater attention may need to be paid to this symptom in people with learning disabilities.

6. Access to healthcare that was problematic for some people who died from COVID-19 included: the responsiveness of NHS111; access to COVID-19 tests; and access to specialist learning disability nurses. Ensuring that these services are fully accessible to people with learning disabilities, their families and paid carers would improve service provision.
7. Reviewers noted in 21% of cases that the need for reasonable adjustments was indicated but such adjustments to service provision had not been made. This was more evident in people who died from COVID-19 than from other causes. The most frequently reported required reasonable adjustments that were NOT made for people who died from COVID-19 were: the provision of specialist learning disability services in hospital; tailoring care provision to meet individual needs; and ensuring the person was supported in unfamiliar settings by those who knew them.
8. Just over half (56%) of people who died from COVID-19 received care that reviewers graded as meeting or exceeding good practice. This was similar to those who died from other causes (63%) and those who died in 2019 (56%). However, this still means that almost half of those who died were considered to have received care that fell short of good practice to some extent.
9. Some concerns were raised about the absence of tools (and the specific equipment required for these, such as oxygen saturation monitors) that can be used to detect acute deterioration in a person's health, particularly in primary care and community settings. Given that one in ten of those who died from COVID-19 had a sudden deterioration in their condition following a period of apparent improvement, it would appear that safety netting and the provision of specific advice about recognising signs of deterioration would be appropriate, particularly in people whose condition appears to be improving.
10. It appears that for at least seven people the virus had been acquired during a previous hospital admission, suggesting a need to strengthen infection control and safe hospital discharges.
11. Several reviewers noted that frailty or 'learning disabilities' were given as rationales for a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision for people who had died from COVID-19, yet this was not the case for people who had died from other causes. Further reminders that 'learning disabilities' or a clinical frailty score are not appropriate reasons for a DNACPR decision in people with learning disabilities may be required.
12. The range of broader impacts of the COVID-19 pandemic were predominantly in relation to: restrictions on face-to-face visits; delays in hospital admissions for routine and emergency care; changes to the availability and skillset of paid carers; and the adverse impact of COVID-19 on end of life care. Other broader impacts of the COVID-19 pandemic were in relation to the closure of day services; delays to existing plans; the isolation of people with learning disabilities; and an increase in clinical responsibilities for family carers.
13. A wide variety of recommendations was made by reviewers in relation to preventing deaths from COVID-19. Some focused on the identification of illness and recognition of deterioration, including the use of specific deterioration tools such as the National Early Warning Score (NEWS2); paying particular attention to the concerns of families and paid carers about subtle signs that a person may be unwell; and the use of pulse oximeters in community settings.

Other clusters of recommendations were in relation to the need for enhanced availability of specialist learning disability nurses in acute hospital settings; the use of 'reasonable adjustments'; and the need to plan proactively to ensure services had sufficiently robust plans for staffing and equipment in case of high demand.

## Main report

### Number of deaths

From 2<sup>nd</sup> March 2020 – 9<sup>th</sup> June 2020, the period that is covered by this report, 1,347 deaths of adults occurred and were reported to the LeDeR programme. Of these, 615 (46%) deaths were from COVID-19; 732 (54%) were from other causes.

In this review of 206 deaths of adults, 163 were from COVID-19; 27% of the total number of COVID-19 deaths occurring during this period.

43 of the deaths included in this report were attributed to other causes – 6% of the total number of deaths from other causes occurring during this 100-day period.

Table 1 presents the number of deaths included in this report by region.

	COVID-19-related deaths		Deaths from other causes		All deaths	
	No.	%	No.	%	No.	%
Midlands	37	23%	11	26%	48	23%
South East	35	22%	8	19%	43	21%
London	30	18%	10	23%	40	19%
North East & Yorkshire	19	12%	3	7%	22	11%
North West	17	10%	9	21%	26	13%
East of England	16	10%	2	5%	18	9%
South West	9	6%	0	0%	9	4%
<i>Total</i>	<i>163</i>	<i>100%</i>	<i>43</i>	<i>100%</i>	<i>206</i>	<i>100%</i>

### The representativeness of the sample of deaths in this report

Table 2 shows the demographic information about those included in this analysis with additional data described in order to assess the representativeness of the sample.

**Table 2: Demographic information about those included in the analysis of 206 deaths and indications of representativeness**

	Adult deaths notified to LeDeR in 2019	Adult deaths notified to LeDeR with confirmed or suspected COVID-19 (Died 2 <sup>nd</sup> March – 9 <sup>th</sup> June 2020)	206 deaths included in this analysis	
			Death from confirmed or suspected COVID-19	Death from other causes
<b>Gender</b>				
Male	57%	59%	56%	63%
Female	43%	41%	44%	37%
<i>Total number*</i>	<b>2,708</b>	<b>612</b>	<b>163</b>	<b>43</b>
<b>Age group</b>				
18-49	23%	17%	21%	21%
50-69	49%	51%	48%	49%
70-84	25%	27%	27%	30%
85 and over	3%	5%	4%	0%
<i>Total number*</i>	<b>2,708</b>	<b>615</b>	<b>161</b>	<b>43</b>
<b>Ethnicity</b>				
White (any)	94%	87%	90%	88%
Asian / Asian British	3%	6%	7%	7%
Black African / Caribbean / Black British	2%	4%	1%	5%
Multiple / mixed or other groups	2%	3%	1%	0%
<i>Total number*</i>	<b>2,576</b>	<b>575</b>	<b>155</b>	<b>42</b>
<b>Level of learning disabilities</b>				
Mild/moderate	66%	65%	64%	68%
Severe / profound & multiple	34%	35%	36%	32%
<i>Total number**</i>	<b>1,952</b>	<b>324</b>	<b>154</b>	<b>41</b>
<b>Usual place of residence</b>				
Own or family home	26%	21%	18%	30%
Supported living	27%	28%	25%	21%
Residential home	30%	30%	35%	33%
Nursing home	15%	19%	19%	9%
Other	2%	3%	4%	7%
<i>Total number**</i>	<b>2,098</b>	<b>342</b>	<b>163</b>	<b>43</b>

N.B. Due to rounding, percentages may not total 100%

\* Total number of notifications for which this information is available

\*\* The information is collected as part of the review process, rather than at notification of the death, so the number relates to completed reviews only.

### *Comparison of COVID-19 deaths in the general population with COVID-19 deaths of people with learning disabilities*

Compared to the general population of people who died from COVID-19 reported by the ONS, our sample of 206 is not statistically different in relation to gender and ethnicity. Comparable data for

usual place of residence and level of learning disabilities were not available for the general population of people who died from COVID-19.

A striking difference between COVID-19 deaths in the general population with the LeDeR sample is in relation to age at death. Office for National Statistics (ONS) data for the general population of England and Wales reports that 47% of deaths from COVID-19 were in people aged 85 years and over. LeDeR data suggests that just 4% of people with learning disabilities who died from COVID-19 were aged 85 years and over – a statistically significant difference.

*Comparison of all deaths notified to LeDeR in 2019 with deaths of people with learning disabilities from COVID-19*

Compared to all deaths notified to LeDeR in 2019, our sample of 163 deaths from COVID-19 is not statistically different in age group, gender, ethnicity, level of learning disabilities or usual place of residence.

*Comparison of all deaths notified to LeDeR with COVID-19, with the sample of deaths from COVID-19 included in this analysis*

The personal characteristics of people with confirmed or suspected COVID-19 whose deaths were notified to LeDeR, and those with confirmed or suspected COVID-19 included in this analysis are broadly similar. There is a slight difference in age at death with a greater proportion of people included in this analysis aged 65 and over (45%), compared to 35% of all those notified with COVID-19, but this difference is not statistically significant.

*Comparison of the sample of deaths from COVID-19 included in this analysis, with the sample of deaths from other causes*

Our sample of 163 deaths from COVID-19 is not statistically different in terms of age group, gender, ethnicity, and level of learning disabilities compared to the 43 deaths from other causes.

## **The people with learning disabilities included in this report**

### ***Usual place of residence***

Table 2 indicates that a third of the deaths included in this analysis (35% of those who died from COVID-19; 33% of those who died from other causes) were of people whose usual place of residence was a residential home. This was the case for 48% of those with Down's syndrome included in the sample.

Approximately a quarter (25% of those who died from COVID-19; 21% of those who died from other causes) lived in supported living settings. Those with autism who died from COVID-19 were more likely to live in a supported living setting (41%, n=9) than those who did not have autism and died of COVID-19 (22%, n=31).

Fewer people who died from COVID-19 usually lived in the family or their own home (18%) than did people who died from other causes (30%). Conversely, more people who died from COVID-19 usually lived in a nursing home (19%), compared to those who died from other causes (9%).

Information about whether a person lived alone or not was not routinely collected for all people.

### ***Pre-existing health conditions***

#### *Genetic conditions:*

##### *Down's syndrome*

Of the 1,107 deaths notified in 2019 that had been reviewed and coded at the time of writing, 18% (n=196) were noted as having Down's syndrome. In this sample of 206 deaths, 20% (n=33) of the 163 who had died with COVID-19 had Down's syndrome; 30% (n=13) of the 43 who died from other causes had Down's syndrome.

##### *Autism*

Of the 1,107 people whose deaths were notified in 2019 that had been reviewed and coded, 10% (n=112) were identified as autistic. In this sample of 206 deaths, 14% (n=22) of the 163 who had died with COVID-19 had autism; 12% (n=5) of the 43 who died from other causes had autism.

##### *Long-term health conditions*

All (100%, n=206) of those included in the sample had at least one long-term health condition. Table 3 shows the most commonly reported long-term conditions in the sample of 206 deaths.

There are no statistically significant differences in the type of long-term conditions between those who died from COVID-19 deaths and deaths from other causes. However, as Table 3 shows, people who died from COVID-19 were more frequently reported to have respiratory conditions (72%), compared to those who died from other conditions (60%). Other conditions more frequently reported in people who died from COVID-19 compared to people who died from other causes were hypertension (33% compared to 21%) and obesity (33% compared to 21%). Given the known associations between these conditions and the likelihood of death from COVID-19 in the general population, these merit further study, and it would seem sensible to introduce precautions for individuals with learning disabilities and these conditions.

People with Down's syndrome who died from COVID-19 were more frequently reported to have had dementia (52%, n=17) than those who did not have Down's syndrome but who died from COVID-19 (9%, n=12).

People with Down's syndrome who died from COVID-19 were also more frequently reported to have had a tendency to fall (55%, n=18) and to have been obese (39%) compared to those who did not have Down's syndrome but who died from COVID-19 (27% and 15% respectively).

Autistic people who died from COVID-19 were more frequently reported to have been obese (45%) compared to those who were not autistic but who died from COVID-19 (30%).

#### Recommendation made by reviewer

'Develop clear protocols during pandemics for care providers and GPs concerning management of infections for people with learning disabilities who may be compromised due to co-morbidities and/or lower physical baselines'.

**Table 3: The most commonly reported long-term health conditions (ordered by prevalence in COVID-19 patients) of those included in the sample**

Long Term Condition	COVID19		Other Causes of Death		Total	
	People with this condition (No.)	People with this condition (%)	People with this condition (No.)	People with this condition (%)	People with this condition (No.)	People with this condition (%)
Mobility impairment	121	74%	32	74%	153	74%
Respiratory conditions	117	72%	26	60%	143	69%
Incontinence	101	62%	31	72%	132	64%
Skin conditions	99	61%	32	74%	131	64%
Mental health needs	96	59%	25	58%	121	59%
Constipation	90	55%	24	56%	114	55%
Sensory impairment	90	55%	28	65%	118	57%
Epilepsy	78	48%	25	58%	103	50%
Cardiovascular disease	56	34%	12	28%	68	33%
Hypertension	54	33%	9	21%	63	31%
Falls	53	33%	20	47%	73	35%
Obesity	53	33%	9	21%	62	30%
Gastric reflux	51	31%	17	40%	68	33%
Dental problems	47	29%	15	35%	62	30%
Hand use impairment	40	25%	9	21%	49	24%
Swallowing issues / dysphagia	32	20%	12	28%	44	21%
Dementia	31	19%	10	23%	41	20%
Diabetes	29	18%	5	12%	34	17%
Osteoporosis	29	18%	6	14%	35	17%
Kidney problems	24	15%	4	9%	28	14%
Cerebral palsy	21	13%	4	9%	25	12%

***Most commonly prescribed usual medications***

People who died from COVID-19 had been prescribed (prior to having COVID-19) an average (mean) of 5.9 regular medications per person, compared to 6.6 for those who died from other causes.

Table 4 shows the names of the most frequently prescribed usual medications in people who died from COVID-19 and those who died of other causes.

**Table 4: The most frequently prescribed usual medications in people who died from COVID-19 and those who died of other causes**

Name of Medication	COVID19		Other Causes of Death		ALL	
	People prescribed this (No.)	People prescribed this (%)	People prescribed this (No.)	People prescribed this (%)	People prescribed this (No.)	People prescribed this (%)
Valproate	35	21	9	21	44	21
Lansoprazole	34	21	4	9	38	18
Levothyroxine	27	17	12	28	39	19
Omeprazole	26	16	11	26	37	18
Senna	25	15	7	16	32	16
Furosemide	22	13	2	5	24	12

As Table 4 shows, people who died from COVID-19 were more frequently prescribed Lansoprazole (21%) and furosemide (13%) than those who died from other causes (9% and 5% respectively), but this was not a statistically significant difference.

There was little difference in the most commonly prescribed categories of medication between those who died from COVID-19 and those who died from other causes. The most marked difference was in the proportion of people taking antiepileptics (33% of those who died from COVID-19 and 40% of those who died from other causes), but this was not a statistically significant difference.

### The prevention and characteristics of COVID-19 infection

#### *Preventative measures to reduce COVID-19 infections*

Some of the key measures to reduce the spread of COVID-19 are 1) for the extremely clinically vulnerable to 'shield' themselves from the possibility of catching the virus; 2) social distancing measures; 3) the use of personal protective equipment (PPE) and face coverings; and 4) handwashing and the use of hand sanitiser<sup>3</sup>.

#### *Shielding*

If people were identified as at high risk of complications from COVID-19 they received a letter from their GP, hospital or other health provider advising them to shield themselves from the virus from the beginning of April 2020. Their name was also held in a central list of 'shielded' patients. Those shielding were informed that they should stay at home at all times and avoid all face-to-face contact for a period of at least 12 weeks.

It is not clear from the completed reviews how many people in the sample of 206 deaths were included in the 'clinically extremely vulnerable' group who were advised to shield. Information about shielding was not provided in the LeDeR review for 69 people (42%).

Reviewers reported that 16 of those who died from COVID-19 had received a letter instructing them to shield. Eleven people who died from COVID-19 had not received a letter instructing them to

<sup>3</sup> <https://www.gov.uk/coronavirus>

shield, but had, nevertheless, been protected as if shielded. For these people, a decision was taken by those who supported them that guidelines for shielding should be followed in order to protect them:

*'William was not on the GP shielding list, the nursing home did not receive a formal letter to confirm William should shield. Despite this the home did follow government guidelines and did not allow visitors in the nursing home'.*

*'May did not receive a shielding letter, but staff had put in place support for her to be shielded as they were aware that she was asthmatic and prone to chest infections'.*

*'Ben did not receive a shielding letter, but he lived in a care home and they decided to shield all the residents'.*

Twenty of the twenty-seven who were shielded or protected as if shielded, but who died from COVID-19, lived in a setting with external paid carers - seven of these people lived in a nursing home, seven in a residential care home and six in supported living settings.

67 people, (41%), were reported to not be shielding.

Recommendation made by reviewer

'All people who have conditions that are known risk factors for COVID-19 should receive a shielding letter'.

### *Social distancing measures*

Social distancing measures were introduced to minimise social interaction between people and reduce the transmission of COVID-19. This included avoiding social gatherings, avoiding non-essential use of public transport, working from home whenever possible, and avoiding contact with anyone displaying symptoms of the virus.

Social distancing measures were, however, problematic for some.

*'Trisha was reliant on others for moving and handling and would not have been able to social distance due to level of physical disability without support from others'.*

In attempts to comply with social distancing measures, there were several examples of nursing/residential homes stopping visits from families and taking other measures:

*'The home locked down due to COVID-19 and family were not able to visit'.*

*'She was supported by care staff to understand why they were wearing full PPE and why her parents and other family members were unable to visit'.*

*'Irene was not attending any Day Services and remained at home. There were no visitors to the home'.*

*'All community based activities had stopped, social distancing measures were in place within the house but this at times proved difficult due to the size of rooms and the house, visitors including family were asked to stay away with contact via video call or phone calls only'.*

Those who died from COVID-19 appeared to have similar experiences to those who died from other causes with regards to social distancing.

### *The use of personal protective equipment, face coverings and hand washing*

PPE is equipment that protects the user against health or safety risks at work. It can include items such as masks, gloves, eye protection, and protective clothing. PPE prevents people coming into contact with the virus in the air, on a person's body or on surfaces. It also reduces the risk of a person passing on the virus to another by covering the mouth, nose, and hands.

PPE was mentioned in almost half of the reviews being analysed here. Generally, reviewers found PPE was available and being used by staff. This was the case for both those who did and did not die from COVID-19:

*'Edward's care provider was trained by the local NHSE PPE Super Trainer in correct use of PPE and were already starting to wear masks in the houses well before government guidance. There is evidence that they followed the Public Health England guidelines in taking measures to prevent the spread of COVID-19, reducing the spread of COVID-19 e.g. isolation and testing'.*

*'Staff used PPE and social distancing and the home had sufficient PPE available.'*

*'Staff supporting Charles during this period used face masks, disposable aprons, gloves and hand sanitisers'.*

Where there were issues with PPE this was in relation to procurement, the impact that seeing staff in facemasks had on those receiving care and support, and confusion about government guidelines:

*'PPE was not supplied for quite a while by the care agency as they wanted Brendan's mother to supply this'.*

*'Henry did not understand the visiting restrictions or the need for staff to wear face masks and [Henry's brother] believes/worries that Henry felt abandoned and alienated'.*

*'PPE was worn because he had symptoms of COVID-19 in line with the national guidance...The guidance was confusing to follow and did not always have all the information that was needed'.*

Where handwashing was mentioned, this was usually alongside reference to PPE protocols:

*'At the entrance of the care home a large toilet room was set up for staff and professionals to change into PPE and wash their hands'.*

*'All staff to abide to infection control measures wearing full PPE, handwashing religiously and using alcohol gel'.*

Face coverings would not have been recommended practice prior to the deaths of the people included in this analysis. However, in line with our finding that many homes went into lockdown before the official date, there were also several reviews that reported that staff in group living settings were using face masks in an attempt to protect residents in the weeks before guidelines were issued for them to do so:

*'The home did not isolate its clients from each other prior to the government lockdown of 23 March 2020 although staff were wearing masks from approximately a week before'.*

Recommendation made by reviewer

'When using PPE recognise the need to adjust communication to counteract the inability to see facial expressions, accommodate changes in speech and take into account hearing or visual loss in patients with learning disabilities'.

### ***The likely source of COVID-19 infections***

For 79 people who died from confirmed or suspected COVID-19, the likely source of infection was other residents or staff in their care home (52%), a recent hospital stay (27%) or from being out and about in the community (18%). For the other 89 people who died from COVID-19, the likely source of the infection was unknown.

Recommendation made by reviewer

'Process is needed to ensure that patients moving from a hot COVID-19 area are no longer COVID-19 positive, to reduce risk of cross contamination and risks to other patients and staff'.

### ***Symptoms of illness***

The key symptoms of COVID-19 are a high temperature, a new, continuous cough, and/or a loss of, or change to, the sense of smell or taste. NHS England reports that most people with COVID-19 have at least one of these symptoms.<sup>4</sup>

In our sample of 206 deaths of people with learning disabilities, a wide range of symptoms that the person was unwell were reported. These are summarised in Table 5.

The most frequently reported symptoms of illness in those who died from COVID-19 were difficulty breathing (77%), a cough (63%) or fever (56%). These symptoms were far more frequently reported in people who died from COVID-19 than in people who died from other causes. Of those who died from COVID-19, 37% had all three symptoms; 39% had two of the symptoms and 21% had one of these symptoms.

None of those who died from COVID-19 were reported to have had a loss of sense of smell or taste, although this is a key symptom in people in the general population.

Lethargy and tiredness also appeared to be more frequently reported in people who died from COVID-19 (39%) compared with other causes (23%).

Other symptoms, such as feeling generally unwell, having a loss of appetite or having diarrhoea or vomiting were similar in those who died from COVID-19 and those who died from other causes.

Recommendation made by reviewer

'In pandemic situations, professionals should actively consider the potential for a patient to have the virus, even if symptoms are atypical, and early preventative measures should be put in place'.

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<sup>4</sup> <https://www.nhs.uk/conditions/coronavirus-COVID-19/symptoms/>

**Table 5: The most commonly reported symptoms of illness in those who died from COVID-19 and those who died from other causes**

Symptom	COVID-19-related deaths		Deaths from other causes	
	Number	%	Number	%
Difficulty breathing	127	78%	14	33%
Cough / 'chesty'	104	64%	13	30%
Fever	93	57%	5	12%
One of the above symptoms only	35	21%	14	33%
Two of the above symptoms	53	39%	6	14%
All three of the above symptoms	61	37%	2	5%
Recent urine or chest infection	64	39%	17	40%
Lethargy/tiredness	64	39%	10	23%
Generally unwell	54	33%	15	35%
Loss of appetite	49	30%	13	30%
Diarrhoea or vomiting	33	20%	9	21%
Confusion	16	10%	3	7%
Sore throat	5	3%	2	5%
Abdominal pain	5	3%	7	16%
Loss of sense of smell or taste	0	-	0	-
Other symptoms	32	20%	14	33%
No symptoms	0	-	3	7%

## Health and care interventions

### Access to healthcare

Access to healthcare has come under scrutiny during the COVID-19 pandemic. The use of NHS111 online and NHS111's role in responding to calls about COVID-19 added a potentially additional layer of complexity for people with learning disabilities. The *COVID-19 rapid guideline: critical care in adults* published by NICE in March 2020<sup>5</sup> recommended the use of a frailty index which disadvantaged people with learning disabilities from accessing critical care. The guideline was changed in April 2020 to clarify that the index ought not be used with people with learning disabilities. We were therefore interested if reviewers reported any problems with accessing healthcare for the people with learning disabilities in the study.

28% (n=45) of the 163 completed reviews of people who died from COVID-19, and 30% (n=13) of the 43 completed reviews of deaths from other causes, noted problems that a person had in accessing timely and appropriate healthcare.

For people who died from COVID-19, problems with access to healthcare were varied and included NHS111 service calls not being returned or returned later than scheduled leading in some cases to an emergency 999 call being used:

<sup>5</sup> <https://www.nice.org.uk/guidance/ng159>

*'When Frances was deteriorating at home, carers could not get through to 111 for a long time'.*

*'Olivia's carers were not contacted within the time frame suggested by the 111 services and when they were contacted it may have given a false impression of the urgency of the need to see a medical professional'.*

*'Carer was not able to get through to 111 so called 999'.*

Access to testing for COVID-19 was also referred to several times in completed reviews and requests for COVID-19 testing in care homes were reported as being declined or unavailable:

*'COVID testing not readily available'.*

*'Inability to test for COVID-19 in the care home setting, particularly in the context of a previous death in the home, may have led to earlier diagnosis and initiation of treatment plans'.*

*'National eligibility criteria discriminated against the learning disability population meaning Katelyn did not qualify for a COVID home testing kit'.*

Support from specialist learning disability services in acute hospitals was also discussed as an issue by several reviewers:

*'The learning disability liaison nurse was not alerted to William's admission'.*

*'ITU staff did not have the expertise of a special learning disability nurse due to capacity'.*

For people who died from other causes, many references to access to healthcare were in relation to access before the pandemic, including it not being known that a person had learning disabilities, and the person not attending or being offered annual health checks or other appropriate services:

*'There was a suggestion by the care home that this man had for some years of his life 'fallen off the learning disability radar' and only picked up in later life'.*

*'Khalil was not offered annual health checks and reasonable adjustments were not made to encourage him to attend GP practice for checks to be completed. Therefore, there were no health action plans or screening to support his health needs'.*

There were also a few instances where the strain on services during the pandemic impacted on access to healthcare:

*'The COVID pandemic and the demands on the NHS (including the redeployment of staff) impacted the availability and effectiveness of services to support Paige. The delay in input from palliative care after Paige's discharge from hospital...was also problematic in that they would normally have picked up the referral within that fortnight - the combination of early pandemic/lockdown and Easter holidays meant staff were not working according to normal routines, and that there was an undesirable delay in following up'.*

Recommendation made by reviewer

'Often the subtle signs that are picked up by carers about a deterioration in health are not always identified within the algorithm [used to prioritise calls to NHS111] so may not trigger an alert. COVID-19 has caused a need to reassess what information is required from individuals contacting

the 111 service, especially when the information is being given on behalf of someone who has communication difficulties. There does not appear to be any acknowledgement of level of concern by a carer’.

### **Place of treatment**

The place of treatment is detailed in Table 6.

<b>Table 6: The place of treatment for those who died from COVID-19 and those who died from other causes</b>				
<b>Place of treatment</b>	<b>COVID-19-related deaths</b>		<b>Deaths from other causes</b>	
	<b>Number*</b>	<b>%</b>	<b>Number*</b>	<b>%</b>
No apparent treatment	8	5%	3	7%
Home-based	31	19%	18	42%
Ward-based	108	66%	20	47%
For escalation to ITU	16	10%	2	5%
Admitted to ITU	14	9%	2	5%

Of those who died from COVID-19, 76% (n=124) had received treatment in hospital; a small proportion (9%, n=14) of these had received some of their treatment in an intensive care unit (ITU), high dependency unit or critical care unit.

Of those who died from other causes, 52% (n=22) had received treatment in hospital; a small proportion (5%, n=2) of these had received some of their treatment in a high dependency unit or intensive care unit.

Recommendation made by reviewer  
 ‘Hospital staff must be responsible for ensuring that the skills and capabilities of care home staff to cope with a patient who has tested as COVID-19 positive and is still unwell are such that they can provide appropriate care and have sufficient PPE before the patient is discharged’.

### **Treatment for COVID-19**

Initially, there was no recommended treatment for COVID-19<sup>6</sup>; most treatment interventions aimed to relieve the symptoms of the virus. Home-based treatments recommended by NHS England include getting lots of rest, drinking plenty of fluids, taking over the counter pain relief and anti-inflammatory medicines, and easing breathlessness through environmental or postural adjustments. Hospital-based treatment may include intravenous fluids and antibiotics, breathing support with the use of oxygen or ventilation, and medication or other treatments to counter the effects of the virus.

Reviewers indicated the treatment that those who had died from COVID-19 had received. This is detailed in Table 7.

<sup>6</sup> Remdesivir and corticosteroids have since been recommended as treatments for COVID-19 in some patients. See: <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/07/C0654-uk-interim-clinical-commissioning-policy-remdesivir-for-patients-hospitalised-with-COVID-19-adults-and-c.pdf> and <https://www.nice.org.uk/guidance/ng159/resources/covid19-prescribing-briefing-corticosteroids-pdf-8839913581>

The majority of those who died from COVID-19 were treated with antibiotics (69%) and / or oxygen (61%).

A small proportion (15%) received mechanical breathing support or ventilation. Of these 25 people, 10 had been treated in an Intensive Care Unit. The remaining 15 people had received ward-based treatment that included Continuous Positive Airway Pressure (CPAP) ventilation (n=4); non-rebreath mask (n=4); Bilevel Positive Airway Pressure (BiPAP) (n = 3); or other support (n=4).

<b>Table 7: The treatment for COVID-19 received</b>		
<b>Treatment received</b>	<b>COVID-19-related deaths</b>	
	<b>Number</b>	<b>%</b>
Antibiotics	113	69%
Oxygen	99	61%
Intravenous fluids	65	40%
Mechanical breathing support/ventilation	25	15%
Dialysis	1	1%

### **Indicators of the quality of care provided**

LeDeR reviewers consider several different aspects of the quality of care provided, including any best practice.

Here we consider indicators of the quality of care for the sample of 206 adults with learning disabilities. These are:

- Examples of best practice provided.
- If there were any concerns about the death.
- If there were any delays in the person’s care or treatment that adversely affected their health.
- If there were any problems with organisational systems and processes that led to a poor standard of care.
- If there were any gaps in service provision that may have contributed to the person’s death.

We also consider:

- The provision of reasonable adjustments.
- The quality of decision-making and use of the Mental Capacity Act.
- The overall grading of the quality of care.

Table 8 shows the indicators of the quality of care reported by LeDeR reviewers for the deaths from COVID-19 or other causes.

**Table 8: Indicators of the quality of care in those who died from COVID-19 and those who died from other causes\***

Indicator of quality of care	COVID-19-related deaths		Deaths from other causes		All	
	Number	%	Number	%	Number	%
Best practice at any time for the person	118	72%	34	79%	152	74%
Concerns about the death	20	12%	4	9%	24	12%
Delays in the person's care or treatment	25	15%	6	14%	31	15%
Problems with organisational systems and processes	27	17%	9	21%	36	18%
Gaps in service provision	9	6%	3	7%	12	6%

\*Each indicator is assessed separately, so the percentage across all indicators does not total 100%

### Examples of best practice

72% (n=118) of reviews of people who died from COVID-19, and 79% (n=34) reviews of people who died from other causes indicated examples of best practice that had occurred at any time for the person.

By 'best practice' we mean care beyond the provision of good quality care that anyone should expect to receive. Some of the descriptions given however, indicated good quality care that should be expected:

*'Mr Stone was monitored annually by his GP for his: learning disability annual review, as well as his kidney disease, hypertension and thyroid reviews...Once Mr Stone started to show signs of illness/COVID-19 carers reacted immediately and correctly..'*

*'The hospital discussed the DNACPR with client...The home staff appear to have a good relationship with the GP.'*

The key areas in which best practice was most frequently reported for people who died from COVID-19 were:

- The involvement of families and paid carers by hospital staff  
*'Despite wards being on 'lockdown' it was made possible for her sister to continue to be with her if she chose to do so'.*
- Communication and coordination between agencies  
*'Discussions and multidisciplinary team meeting held with...specialities at consultant level during Marie's admission'.*
- A person-centred approach  
*'During Eleanor's final days she could not have any staff visit her that she knew or have any of her belongings due to COVID-19. Staff made efforts to source a teddy bear for her and a knitted blanket to put on her bed to provide comfort'.*
- Rapid response to COVID-19  
*'Care provider made the decision to shield residents before official guidance was issued... that this may have potentially prevented spread of the infection'.*

The key areas in which best practice was most frequently reported for people who died from other causes were:

- End of life care  
*'Co-ordination of care by the hospice and support for Rebecca and her family following discharge from hospital for palliative care / end of life care'.*
- Communication and coordination between agencies and with families  
*'There was very good interagency joint working and communication. All services were very responsive to Rose and the carers' needs'.*

Recommendation made by reviewer

'Case studies of good multi-professional and cross-organisational working practices with positive outcomes should be disseminated as good practice examples for all health and social care staff working with people with learning disabilities'.

### *Concerns about the death*

The majority of reviewers (88%) indicated that no concerns had been raised about the death. The corresponding proportion for deaths of adults with learning disabilities reported in the most recent LeDeR programme annual report<sup>7</sup> was also 88%.

Concerns were raised in relation to 12% (n=20) of people who died from COVID-19. There was a wide range of concerns, but they were most commonly in relation to:

- Aspects of clinical / nursing care  
*'His family are not sure whether everything was done in hospital to prevent or minimise the risk of Joseph dying'.*
- Hospital discharge arrangements  
*'Liam was sent home after 4 days in hospital when he had been diagnosed with COVID-19 and was still unwell and very lethargic... When [the care home manager] contacted the hospital on the day of his discharge to express these concerns she was informed the hospital directive was to send all patients home if able to maintain own oxygen levels'.*
- Infected with COVID-19 in hospital  
*'His brother suspects that Cameron may have contracted COVID-19 in the hospital. They were informed by the learning disability nurse that Cameron was COVID-19 positive 19 days after his admission to hospital'.*
- Not recognising deterioration of condition  
*'Increased NEWS (National Early Warning Score) was not responded to on the evening prior to Noels death and action not taken at the ward round'.*

Concerns were raised in relation to 9% (n=4) of people who died from other causes. All were related to aspects of the quality of care received by the person who had died.

### *Delays in the person's care or treatment that adversely affected their health*

Reviewers were asked if, from the evidence they had, they felt there were any delays in the person's care or treatment that had adversely affected their health. The majority of reviews (85%, n=175)

<sup>7</sup> [www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR\\_2019\\_annual\\_report\\_FINAL2.pdf](http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf)

indicated that there had been no such delays. The corresponding proportion for deaths of adults with learning disabilities reported in the most recent LeDeR programme annual report<sup>8</sup> was 87%.

Delays were reported in relation to 15% (n=25) of people who died from COVID-19. The most frequently reported delays were in relation to:

- Delays in treating COVID-19, including delays in admitting a person to hospital  
*'It is possible that concerns around hospital acquired infection led to a delay in admitting Donald'.*
- Problems with testing people for COVID-19  
*'Staff...were unable to source a COVID testing kit for Neave as she did not meet the criteria. Services did not consider what reasonable adjustments needed to be made for Neave to be tested as she was not able to access a local testing centre'.*
- Delays with provision of care that were not related to COVID-19  
*'Medical advice was not sought for Adam's pressure sore until it reached the 'ungradable' stage'.*

Delays were reported in relation to 14% (n=6) of people who died from other causes. These were related to delays in the general provision of care:

*'Care home staff also queried if Nichola's eating difficulties could have been investigated more thoroughly and earlier'.*

#### *Problems with organisational systems and processes that led to a poor standard of care*

Based on the evidence they had, reviewers were asked if they thought that there were any problems with organisational systems and processes that led to a poor standard of care for the person. The majority (82%, n=170) of reviews reported no such problems. The corresponding proportion for deaths of adults with learning disabilities reported in the most recent LeDeR programme annual report<sup>9</sup> was 87%.

Problems with organisational systems and processes were reported in relation to 17% (n=27) of people who died from COVID-19. The problems were various, but those specifically related to risk factors for COVID-19 or care during the pandemic were:

- Coordination of care / links between agencies  
*'Primary care, specialist care and the home did not refer to public health or dietetic services for weigh loss advice. Despite being obese there is no record of the risks and/or any management plan'.*
- Communication  
*'Once admitted...the family were ringing daily to try and get information and struggled to get a member of staff that could update [them]. They would have liked the ward to have a dedicated family liaison worker'.*
- Statutory guidance not followed  
*'The absence of a MCA capacity assessment followed-up by a best interests meeting'.*
- End of life care

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<sup>8</sup> [www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR\\_2019\\_annual\\_report\\_FINAL2.pdf](http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf)

<sup>9</sup> [www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR\\_2019\\_annual\\_report\\_FINAL2.pdf](http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf)

*'The use of "local" paperwork was not supported by a recognised tool such as ReSPECT which may have influenced the paramedic's decision to not transfer her to hospital. It [a ReSPECT form] would also have provided the contact details for the IMCA involved with Maggie'.*

Problems with organisational systems and processes were reported in relation to 21% (n=9) people who died from other causes. The most commonly reported problem was related to communication and coordination between and within agencies:

*'She missed her final annual health check due to staffing issues and had no co-ordination of her physical health needs and no shared health action plan, rather she was seen for each problem separately'.*

#### *Gaps in service provision that may have contributed to the person's death*

Most reviews (94%, n=194) reported no gaps in service provision that may have contributed to the person's death. The corresponding proportion for deaths of adults with learning disabilities reported in the most recent LeDeR programme annual report<sup>10</sup> was 93%.

Gaps in service provision that may have contributed to the person's death were reported in relation to 6% (n=9) of people who died from COVID-19. The most frequently reported gap was the knowledge about or utilisation of specialist sources of support:

*'The population at (care home) is largely frail older people and people with physical disabilities. Graham was one of only 2 residents there with a learning disability and staff lacked the skills to engage with him in an appropriate way'.*

Gaps in service provision that may have contributed to the person's death were reported in relation to 7% (n=3) of people who died from other causes. The numbers are too small for any discernible themes to be identified.

Recommendation made by reviewer

'COVID wards to enable learning disability liaison [nurse] presence...to increase support to staff to provide a high quality of care'.

#### ***The provision of reasonable adjustments***

Under the Equality Act 2010<sup>11</sup> public sector organisations have to make changes in their approach or provision to ensure that services are accessible to disabled people. 'Reasonable adjustments' are those changes to the usual ways of doing things that take account of a disabled person's individual needs. Reviewers are asked if any reasonable adjustments had been made for a person and if so, what these were. They are also asked to note if any reasonable adjustments should have been made but were not.

Information about the provision of reasonable adjustments was not included in 27% (n=54) of the reviews (43 deaths from COVID-19; 11 deaths from other causes).

Of the 152 reviews where information was available about the provision of reasonable adjustments, the majority (80%; n=121) of reviewers noted that reasonable adjustments had been made for the

<sup>10</sup> [www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR\\_2019\\_annual\\_report\\_FINAL2.pdf](http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf)

<sup>11</sup> <https://www.legislation.gov.uk/ukpga/2010/15>

person. Many of the adjustments made were in relation to whole groups of people (e.g. the provision of a specialist learning disability nurse); a smaller number were more individually focused (e.g. the provision of individually tailored support for an individual).

The most frequently reported reasonable adjustments made were:

- The provision of learning disability nurse/access to specialist learning disability services whilst in hospital  
*'On admission the learning disability nurse highlighted specific care management. The learning disability team provided written and verbal instruction to the ward staff regarding interventions with Richard'.*
- The use of Hospital Passports, detailing a person's individual needs  
*'Detailed hospital passport and Shared Lives plan went with Paul when he was admitted to hospital'.*
- Carers/family members being able to accompany or stay with people in hospital  
*'Father was supported to stay with Samira in the hospice. This was a risk-based decision taken by the hospice team as it was during the pandemic period when visitors to in-patient and care settings were not taking place. Mr Abbas was given the appropriate PPE and was able to remain in Samira's room and use the en-suite facilities'.*

There were no obvious differences between those who died from COVID-19 and those who died from other causes in relation to the reasonable adjustments that were provided during this time.

The importance of these reasonable adjustments is highlighted by reviewers noting when such adjustments were required, but not made. 20% (n=31) of reviewers noted that reasonable adjustments should have been made for a person but had not (18% of people who died from COVID-19; 7% of people who died from other causes).

The most frequently overlooked adjustments for people who died from COVID-19 were:

- Provision of learning disability services whilst in hospital  
*'The Acute Liaison Nurses did not receive contact about this patient as she was not identified as having a learning disability on the hospital system'.*
- Meeting individual needs/providing a personalised service  
*'GP should have considered the use of easy read information as it was recorded that Iain did not understand some of the information being given to him by phone'.*
- Carers/family members unable to accompany or visit whilst in hospital  
*'The family were unable to see Sonia in hospital due to the COVID-19 restrictions at the hospital. Family were very upset that she had to live her last days alone'.*

Recommendation made by reviewer

*'In the event of a potential second wave of COVID-19 hospitals should make reasonable adjustments for visitors to be with a relative'.*

### **Decision-making and the use of the Mental Capacity Act**

The Mental Capacity Act 2005<sup>12</sup> (MCA) clarified the law in England and Wales about how decisions should be made on behalf of those who lack mental capacity. It was accompanied by a Code of Practice providing guidance on the implementation of the five key principles of the Act.

Essentially, the Act requires that if it is established that a person lacks the capacity to make a specific decision, the decision must be made in their 'Best Interests', which requires consultation with close relatives or friends and anyone engaged in caring for them, or anyone legally authorised to make decisions for the person. In addition, everything possible should be done to encourage the person to take part in the decision-making. The Act specifies that assumptions should not be made on the basis of age, appearance, condition, or behaviour.

There has been a plethora of recommendations about improving adherence to the MCA from other reports and inquiries<sup>13</sup>.

LeDeR reviewers are asked to describe any decisions where there is evidence that a mental capacity assessment took place and, if indicated, a best interests decision-making process was followed. They are also asked to describe any decisions around which they thought a mental capacity assessment and best interests decision-making process should have taken place but did not.

Of the 153 reviews where information was available about adherence to the Mental Capacity Act, 25% (n=38) of reviewers noted that they thought a mental capacity assessment and best interests decision-making process should have taken place but did not (31 deaths from COVID-19; 7 deaths from other causes).

The most frequently reported decisions for which a mental capacity assessment and best interests decision-making process should have taken place but did not, for people who died from COVID-19 was in relation to DNACPR orders. Numerous reviewers noted the lack of evidence of a mental capacity assessment in relation to this:

*'Mental Capacity Assessment/Best Interest discussions/decisions when admitted to hospital...No documentation was evidenced, no record of family involvement, no evidence of discussion with patient around his care'.*

*'Concerns have been raised by his social worker and the learning disabilities community nurse regarding the completion of the DNACPR and Treatment Escalation Plan in accordance with the Mental Capacity Act which prevented Gareth being admitted to hospital for treatment following the onset of COVID symptoms'.*

*'DNACPR...No capacity assessment documented, no IMCA appointed; Escalation of care...No capacity assessment documented, no IMCA appointed'.*

*'Capacity referenced as lacking but not assessed...DNACPR challenged by learning disability liaison nurse'.*

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<sup>12</sup> <https://www.legislation.gov.uk/ukpga/2005/9/contents>

<sup>13</sup> For a summary see: [http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR\\_2019\\_annual\\_report\\_FINAL2.pdf](http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_2019_annual_report_FINAL2.pdf)

The most frequently reported decisions for which a mental capacity assessment and best interests decision-making process should have taken place but did not, for people who died from other causes were in relation to care during the COVID-19 pandemic, and relating to specific medical conditions:

*'No evidence of a formal assessment of Gloria's capacity around COVID measures. Gloria had dementia and was dependent on staff for all of personal care needs including the need to protect herself from COVID-19'.*

*'No evidence of Best Interest discussion or capacity assessment...Abdominal Aortic Aneurism (AAA) screening was not attended'.*

Recommendation made by reviewer

'Strengthen MCA assessment processes and documentation of decisions among care providers'.

### **Overall assessment of the quality of care**

At the end of their review, having considered all the evidence available to them, reviewers are requested to provide an overall assessment of the quality of care provided to the person.

The grading is as follows:

1. Care met or exceeded good practice.
2. Care fell short of current good practice in one or more minor areas, but this did not significantly impact on the person's well-being.
3. Care fell short of expected good practice in one or more significant areas, but this did not significantly impact on the person's well-being.
4. Care fell short of expected good practice and this significantly impacted on the person's well-being and/or had the potential to contribute to the cause of death.
5. Care fell far short of expected good practice and this contributed to the cause of death.

Figure 1 presents the reviewer assessment of the quality of care provided to adults with learning disabilities who died from COVID-19, and those who died from other causes.

As Figure 1 shows, 56% of people who died from COVID-19 and 63% of those who died from other causes received care that reviewers graded as meeting or exceeding good practice. The corresponding proportion of deaths reviewed in 2019 was also 56%.

Care received by 2% of those who died from COVID-19 and 2% of those who died from other causes both groups was recorded as falling so short of good practice it had a significant impact on the person's health. The corresponding proportion of deaths reviewed in 2019 was 4%.

Care that was considered to have fallen short of good practice and impacted on the person's health or wellbeing or contributed to the cause of death was most frequently due to delays in the diagnosis and treatment of people.

*'Aidan's elevated NEWS score was not responded to the night before his death'.*

*'No advice about management from GP although it was Friday – no plan for the weekend. No Oxygen sats or resp [respiratory] rate recorded by GP. No risk assessment re COVID-19'.*

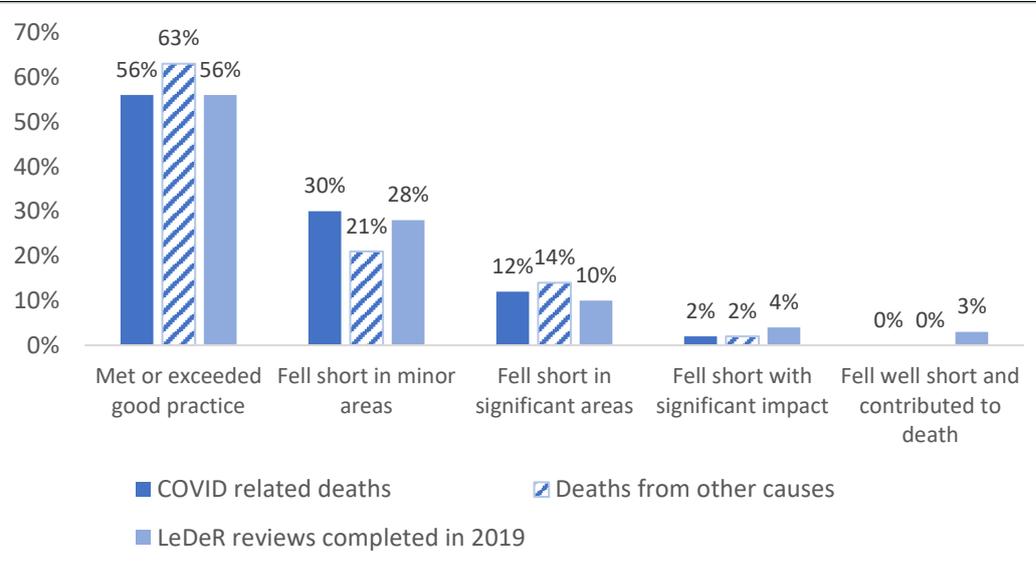
Other reasons for these grades being given were a lack of proactive care, the provision of poor-quality care, and deficiencies in monitoring existing health conditions.

*'Lianne's challenging behaviour may have been due to pain ...her pain was not adequately assessed and managed'.*

*[There was a] 'lack of monitoring of long-term health condition - had COVID-19 not impacted upon her service provision, emerging changes in presentation from a kidney infection may have been detected earlier'.*

*'Derek was less mobile and active during COVID lockdown and this may have contributed to the development of a pressure ulcer which went unnoticed by his carers'.*

**Figure 1: Reviewer assessments of the quality of care provided to adults with learning disabilities who died from COVID-19, those who died from other causes and all LeDeR reviews completed in 2019**



**Recommendation made by reviewer**  
 'Ensure we continue to think 'outside the box' for people with learning disabilities and not be forced down care pathways that are not moveable because "one size does not definitely fit all".'

**The deaths of the people with learning disabilities included in this report**

***Time from symptoms to death***

Information about the time from symptoms being noticed to the receipt of treatment was available for 126 people who died from COVID-19, and for 23 people who died from other causes. Almost all received medical treatment within 7 days of their symptoms being apparent (Table 9).

Information about the time from symptoms being noticed to the person's death was available for 91% (n=149) deaths of people who died from COVID-19 and 70% (n=30) of those who died from other causes. Few people who died from COVID-19 did so within 24 hours of their symptoms being recognised; the majority (37%) died more than 8 days after the development of symptoms.

<b>Table 9: Time from symptoms to medical treatment / death those who died from COVID-19 and those who died from other causes</b>				
<b>Time to treatment</b>	<b>COVID-19-related deaths</b>		<b>Deaths from other causes</b>	
	<b>Number</b>	<b>%</b>	<b>Number</b>	<b>%</b>
Less than 24 hours	84	67%	15	65%
More than 24 hours but less than 72 hours	31	25%	5	22%
Between 72 hours and 7 days	11	9%	1	4%
Between 8 and 14 days	0	-	1	4%
More than 14 days	0	-	1	4%
Total 'known'	126	100%	23	100%
<i>Total not known</i>	37		20	
<b>Time to death</b>				
Less than 24 hours	6	4%	8	27%
More than 24 hours but less than 72 hours	17	11%	4	13%
Between 72 hours and 7 days	30	20%	6	20%
Between 8 and 14 days	41	28%	1	3%
More than 14 days	55	37%	11	37%
Total 'known'	149	100%	30	100%
<i>Total not known</i>	14		13	

### **Recognition of deterioration prior to death**

It is vital that indications that a person's health is deteriorating are detected and recognised promptly, and action is taken to escalate care. NEWS2 is endorsed by NHS England and NHS Improvement as the recognised early warning system for identifying acutely ill and deteriorating patients in hospitals in England. It is also, increasingly, being used in primary care and community settings.

Almost a quarter (23%, n=37) of people who died from COVID-19, and 12% (n=5) of those who died from other causes had one or more NEWS2 scores recorded.

It appeared that some NEWS scores were a single recording to support decision-making:

*'NEWS score of 10. Ambulance called....paramedics attended...diagnosed as probable severe acute respiratory syndrome - coronavirus. ...admitted to ward'.*

On other occasions, it was the change in a succession of NEWS2 scores that provided an indication of deterioration in a person's health:

*'Nurse in charge noted raised NEWS scores on commencement of the shift. Previous evenings had been within normal limits'.*

Some concerns were raised about the absence of tools used to detect acute deterioration in a person's health, particularly in primary care and community settings:

*'Support staff not familiar with early detection of deterioration in health'.*

*'No evidence of deterioration/escalation scores used to assess Anne by 111/GP'.*

In addition, there were several recommendations made about the need for clearer guidance for families and paid carers about identifying acute deterioration specifically in relation to COVID-19:

*'Develop clear protocols during pandemics for care providers and GPs concerning management of infections for people with learning disability who may be compromised due to co-morbidities and/or lower physiological baselines. This should include provision of monitoring equipment and development of deterioration and escalation tools.'*

*'Develop a specific deterioration tool for use in the care home settings when COVID-19 suspected.'*

Tools that can help identify acute deterioration in a person usually rely on measuring a number of physiological states, some of which (oxygen saturation, systolic blood pressure, temperature) require specific equipment. A number of comments were made about the lack of availability of such equipment in family or care homes and the need for this to be rectified:

*'A plan needs to be developed with local authorities to ensure the availability of oxygen saturation equipment and training of staff to use this'.*

*'Manager at [name of care home] has requested that an oxygen saturation monitor is purchased for the house...this could assist staff in deciding if additional medical assistance is required for an individual'.*

For some people, relying entirely on a monitoring tool or algorithm needed to go hand-in-hand with picking up on the 'softer' signs that a person was becoming more unwell and listening to those who know them best:

*'Often the subtle signs that are picked up by carers about a deterioration in health are not always identified within the algorithm [used to prioritise calls to NHS111] so may not trigger an alert. COVID-19 has caused a need to reassess what information is required from individuals contacting the 111 service, especially when the information is being given on behalf of someone who has communication difficulties. There does not appear to be any acknowledgement of level of concern by a carer'.*

Recommendation made by reviewer

'Explore if thresholds for referral into hospital for patients with learning disabilities with suspected COVID-19 need to be different from the general population taking into account differing physiological baselines'.

Recommendation made by reviewer

'A plan needs to be developed with local authorities to ensure the availability of oxygen saturation equipment and training of staff to use this'.

### ***Circumstances leading to death***

For those who died from COVID-19 and for those who died of other causes, there was usually a steady deterioration leading to death.

A small proportion of those who died from COVID-19 (11%, n=18) experienced a sudden deterioration in their health prior to death, a similar proportion to those who died from other causes (14%, n=6). Examples of improvement before a sudden deterioration included:

- Discharge planning taking place (person not on end of life care).
- Discharged from hospital (person not on end of life care).
- Assessed as 'medically fit'.
- Planning to wean off active treatment following improved oxygen saturation levels.
- Reduced fever and cough.
- Reports that a person felt better, and their condition was improving.
- Being discharged from critical care to a ward due to improvements.

The sudden deterioration in health for those who died from COVID-19 was often related to a return of the symptoms of COVID-19 following a period of apparent improvement, an exacerbation of symptoms, or the development of new symptoms of the virus. For those who did not die from COVID-19, the sudden deterioration in their health was usually related to a long-term illness, was not an unexpected deterioration, or it followed an accident.

More than one in ten (14%; n=23) of those who died from COVID-19 were readmitted to hospital after having been recently discharged. This was a greater proportion than those who died from other causes (5%, n=2).

*'Dr Bashir felt that the hospital had perhaps discharged Ryan too early due to concerns that he could be at risk of contracting coronavirus whilst on the ward. He went on to advise that should Ryan continue to deteriorate, he should return to hospital for treatment'.*

*'Admitted to [hospital] with increased breathlessness. Discharged back home and re-admitted [the following day] after urgent call to GP'.*

The majority of people who died from COVID-19 who had been readmitted to hospital were admitted on both occasions with symptoms of COVID-19. For a small number (n=7) symptoms of the virus were not the reason for the first hospital admission, but they were for the second. It may be that for these people, the virus may have been acquired during the first admission.

There were also instances where it seemed that a person should have been admitted to hospital but was not, or where delays in their admission negatively affected the person: 14% (n=23) of the people who died from COVID-19 did not access hospital care before their death although this was indicated:

*'[Ambulance service] staff reluctant to take Ayesha to hospital in the current climate'.*

*'There was a potential delay in getting John to hospital for a full assessment when he had early signs for COVID-19 and the ambulance crew made their initial visit...This may have been due to lack of clarity for COVID-19 assessment processes for the ambulance crew or a reluctance to take him to hospital for fear he would become infected with COVID-19'.*

*'Productive cough - green sputum...Sats [oxygen saturation] dropping to 87% at times on 3l of oxygen...Paramedics recommended she try different antibiotic. They warned her no capacity in hospital. [Following day] Attended with respiratory failure...COVID-19 was suspected and confirmed....transferred to a medical ward where she died shortly afterwards'.*

For those who died from causes other than COVID-19, the lack of hospital admission leading to death appeared appropriate because the death was either expected and the person was

comfortable at home, or in some cases deterioration was sudden and the person died before being admitted to hospital.

Recommendation made by reviewer

'Where there have been multiple contacts with a patient or carer on behalf of a patient, Call Handlers to ensure a clinician becomes involved'.

Recommendation made by reviewer

'To explore further what learning disability training 999 call handlers have in relation to managing people with a learning disability when they are distressed'.

### ***Cause of death***

We examined the underlying causes of death in the sample population<sup>14</sup>.

#### *Underlying cause of death*

The World Health Organisation defines the underlying cause of death as the disease or injury which initiated the train of events leading directly to death, or the circumstances of the accident or violence which produced a fatal injury.

Information about the underlying cause of death was available for 141 who died from COVID-19 and 37 who died from other causes.

Of those who died from COVID-19, two-thirds (65%, n=92) had the underlying cause of their death recorded as COVID-19 (Table 10). The other most frequently recorded underlying causes of death for people who died from COVID-19 were diseases of the respiratory system (14%).

Of those who died from other causes, the underlying cause of their deaths was more varied as would be expected (Table 10). The most frequently recorded underlying causes of death were diseases of the respiratory system (38%) and congenital malformations, deformations and chromosomal abnormalities (19%).

Six people with Down's syndrome had Down's syndrome described as their underlying cause of death. Five of these had died from other causes; one had died from COVID-19. As we commented in our last annual report, by recording Down's syndrome as an underlying cause of death, it conceals the more specific causal sequence of events leading to the person's death.

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<sup>14</sup> Caution must be taken in interpreting this data as we have not yet received the official ICD-10 codes for the causes of death as presented on the Medical Certificate of Cause of Death (MCCD). Thus, the reviewer may not have seen MCCD and written what they believed to be the cause of death.

**Table 10: The most frequently recorded underlying causes of death, by ICD10 chapter and condition, for those who died from COVID-19 and those who died from other causes**

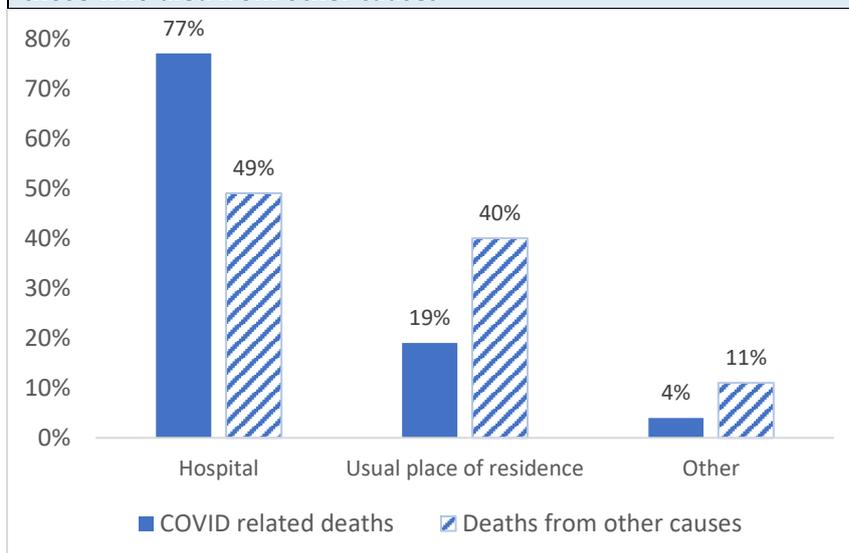
ICD10 chapter	COVID-19-related deaths		Deaths from other causes	
	Number	%	Number	%
U07.01 Emergency code for coronavirus	92	65%	0	-
J00-J99 Diseases of the respiratory system	19	14%	14	38%
H00-I99 Diseases of the circulatory system	6	4%	4	11%
G00-G99 Diseases of the nervous system	5	4%	1	3%
Q00-Q99 Congenital malformations, deformations and chromosomal abnormalities	2	1%	7	19%
Other underlying causes of death	17	12%	11	30%
Total 'known'	141	100%	37	100%
Missing	22		6	

### Place of death

Figure 2 shows the place of death for those who died from COVID-19 and those who died from other causes.

Of those who died from COVID-19, 77% died in hospital; the corresponding proportion for people who died from other causes was 49%.

**Figure 2: the place of death of people who died from COVID-19 and those who died from other causes**



### ***Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions<sup>15</sup>***

We reported in our last annual report that of 1,875 deaths of adults reviewed in 2019 for whom data was available about DNACPR decision, 72% had such a decision. Reviewers felt that the majority of these (78%) were correctly completed and followed:

Information about DNACPR decisions was available for all our study population.

Of those who died from COVID-19, 82% had such a decision. Reviewers felt that the majority of these (72%) were correctly completed and followed.

*'Carried out with hospital staff and next of kin, clearly documented Mental Capacity Act assessment and best Interests decision'.*

The reasons given for DNACPR decisions not to be correctly completed and followed in people who died from COVID-19 were various, but several reviewers noted that frailty or 'learning disabilities' were given as a rationale<sup>16</sup>:

*'Initial DNACPR completed incorrectly stating learning disabilities as reason for completion. "wheelchair bound, needs to be hoisted, care home resident, learning disability". [This was] completed and rewritten on the advice of learning disabilities liaison nurse. Teaching session delivered on the ward. Subsequently rewritten as "advanced comorbidities which are likely to make cardiopulmonary resuscitation individually unsuccessful".'*

*'DNACPR not completed fully in hospital (none in community) including section regarding discussion with next of kin/others. Use of Fragility Scale was given in rationale alongside comorbidities'.*

Several reviewers also noted that the decision-making process for DNACPR decisions had not adhered to the Mental Capacity Act (MCA):

*'DNACPR signed – records state no next of kin details therefore not contacted. No MCA assessment undertaken at this time. Order documented as indefinite'.*

*'The DNACPR was completed without input from next of kin or carers who knew her'.*

Of those who died from other causes, 72% had such a decision. Again, reviewers felt that the majority of these (87%) were correctly completed and followed:

*'The DNACPR [decision] was reviewed every three months by the learning disabilities team'.*

*'Initially there were issues relating to a RESPECT document<sup>17</sup> completed by the GP in light of COVID. The hospital felt the information within was confusing and unclear and needed to be reviewed taking into account the opinions of others'.*

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<sup>15</sup>Cardio-pulmonary resuscitation is when a person receives chest compressions and artificial breaths to help pump blood around their body when their heart has stopped. A decision not to attempt cardio-pulmonary resuscitation is made and recorded in advance when it would not be in the best interests of the person because they are near the end of their life or the procedure would be unlikely to be successful.

<sup>16</sup>On 25 March 2020, NICE clarified that the Clinical Frailty Scale should not be used for younger people, people with stable long-term disabilities, learning disabilities or autism.

<sup>17</sup> The ReSPECT process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices. The recommendations are created through conversations between a person, their families, and their health and care professionals to understand what matters to them and what is realistic in terms of their care and treatment.

The reason given for DNACPR decisions not to be correctly completed and followed in people who died from other causes was related to whether the correct process had been followed:

*'The completed DNACPR indicates Laura had capacity. Section 3 indicates discussion with hospital palliative care team but does not indicate if there was a discussion with Laura. Discussion with father recorded in Section 4 and indicates he agrees with decision. Document completed / signed by associate palliative care practitioner and countersigned by clinical nurse specialist.'*

None of those who died from causes of death unrelated to COVID-19 had DNACPR decisions made on the basis of a frailty score or because the person had 'learning disabilities', and none stated that the process had not adhered to the MCA.

Recommendation made by reviewer

'ReSPECT is not well known enough and is still being completed when individuals are often too ill to be involved in the decision making for themselves...Greater promotion of the use of this tool should be undertaken by all agencies supporting individuals with a learning disability'.

**Broader impacts of COVID-19 on the lives of people with learning disabilities**

A range of broader impacts of the COVID-19 pandemic were mentioned in completed reviews. These were predominantly in relation to four key issues:

1. That face-to-face visits were restricted and contact with the person by families or professionals was by telephone or video link.  
*'Due to guidelines his mother was unable to visit Neil. Face to face discussion with professionals may have resolved any concerns from [his mother] and established her understanding of his condition and prognosis.'*  
  
*'Due to COVID-19 restrictions the physiotherapy team made regular telephone contacts to home every 2 weeks. [They were] unable to speak personally to Rowan as she refused requests to speak on the telephone...[offers to] communicate via WhatsApp, skype and zoom during this period were also refused by Rowan.'*
2. Delays in the provision of clinical care, particularly hospital admissions for both routine and emergency care.  
*'Chemotherapy was not being offered to people of Daniels age due to COVID-19 and the risk of infection'*  
  
*'Ewan had had a scan booked for his pancreas ...but this was cancelled due to the COVID risk'*
3. Changes to the availability and skillset of paid carers, particularly due to sick leave within the organisation.  
*'The COVID pandemic and the demands on the NHS (including the redeployment of staff) impacted on the availability and effectiveness of services to support Ms Brown'*  
*'The home was using 12-hour shift patterns to avoid cross over of staff due to COVID-19 and infection control'*

4. The impact of COVID-19 on end of life care and funeral arrangements

*'The carers at his usual place of care tried to ensure his end of life wishes were met but due to COVID certain wishes were not able to be followed through'.*

*'The inclusion of COVID-19 on Helen's death certificate caused her family problems with arranging her burial as most of the mosques they approached refused to do it. Eventually a mosque that is far away from where they live agreed to do it but charged an extra £2,000 because of the COVID diagnosis'.*

Other broader impacts of the COVID-19 pandemic were in relation to the closure of day services, delays to existing plans, the isolation of people with learning disabilities, and an increase in clinical responsibilities for family carers.

Recommendation made by reviewer

An 'emergency allowance' [should be] built in to care packages where foreseeable difficulties may arise'.

Recommendation made by reviewer

'Risk analysis to be in place to manage episodes of high levels of staff sickness with a strategy on where to recruit short term staff '.

Recommendation made by reviewer

'Providers should ensure they have appropriate contingency plans and additional sources of equipment in the event of equipment breaking or high demand'.

**Recommendations from reviewers and suggestions for service improvement**

We have drawn together recommendations made by reviewers to improve service provision for people with learning disabilities and grouped these into themes<sup>18</sup>. Table 11 shows a selection of the recommendations specific to COVID-19; Table 12 indicates some other broader recommendations for service improvements for people with learning disabilities.

Seventy-six recommendations were in relation to COVID-19.

A cluster of the recommendations focused on the identification of illness and recognition of deterioration. Amongst these, recommendations included the use of specific deterioration tools such as NEWS2; paying particular attention to the concerns of families and paid carers about subtle signs that a person may be unwell; and the use of pulse oximeters in community settings.

Other clusters of recommendations were in relation to the need for enhanced availability of specialist learning disability nurses in hospital settings; the use of reasonable adjustments to enable people with learning disabilities to have a familiar person with them in hospital; safe hospital discharge; the availability and use of Personal Protective Equipment (PPE); COVID-19 testing for staff and residents; the need for bereavement support as appropriate; and the need to plan proactively to ensure services had sufficiently robust plans for staffing and equipment in case of high demand.

<sup>18</sup> Some of these have already been presented elsewhere in this report. They are summarised here together.

**Table 11: Selection of recommendations from reviewers related to COVID-19**

'Develop a specific deterioration tool for use in the care home settings when COVID-19 is suspected'.

'In pandemic situations, professionals should actively consider the potential for a patient to have the virus, even if symptoms are atypical, and early preventative measures should be put in place'.

'Develop clear protocols during pandemics for care providers and GPs concerning management of infections for people with learning disabilities who may be compromised due to co-morbidities and/or lower physical baselines'.

'Often the subtle signs that are picked up by carers about a deterioration in health are not always identified within the algorithm [used to prioritise calls to NHS111] so may not trigger an alert. COVID-19 has caused a need to reassess what information is required from individuals contacting the 111 service, especially when the information is being given on behalf of someone who has communication difficulties. There does not appear to be any acknowledgement of level of concern by a carer'.

'Explore if thresholds for referral into hospital for patients with learning disabilities with suspected COVID-19, need to be different from the general population taking into account differing physiological baselines'.

'All...providers should have access to an oximeter'.

'COVID wards to enable learning disability liaison [nurse] presence...to increase support to staff to provide a high quality of care'.

'In the event of a potential second wave of COVID-19 hospitals should make reasonable adjustments for visitors to be with a relative'.

'In the event of a second wave of COVID, discharge teams have agreed protocols for cross border discharge'.

'Process is needed to ensure that patients moving from a hot COVID-19 area are no longer COVID-19 positive, to reduce risk of cross contamination and risks to other patients and staff'.

'Hospital staff must be responsible for ensuring that the skills and capabilities of care home staff to cope with a patient who has tested as COVID-19 positive and is still unwell are such that they can provide appropriate care and have sufficient PPE before the patient is discharged'.

'If there is a further lockdown for clear advice to be given about use of Agency staff to minimise spread of COVID-19'.

'Request to be made...for earlier screening of staff...should similar circumstances recur'.

'When using PPE recognise the need to adjust communication to counteract the inability to see facial expressions, accommodate changes in speech and take into account hearing or visual loss in patients with learning disabilities'.

'Put in place appropriate explanations of PPE for patients with learning disabilities in acute trust settings'.

'All people who have conditions that are known risk factors for COVID-19 should receive a shielding letter'.

'Support and bereavement counselling to be provided for all ...affected by the loss of someone from COVID-19'.

An 'emergency allowance' [should be] built in to care packages where foreseeable difficulties may arise'.

'Risk analysis to be in place to manage episodes of high levels of staff sickness with a strategy on where to recruit short term staff '.

'Providers should ensure they have appropriate contingency plans and additional sources of equipment in the event of equipment breaking or high demand'.

Table 12 indicates some of the other broader recommendations for service improvements made. It should be noted that all of these have been made at the time of the COVID-19 pandemic, so may well be indirectly related to service provision at that time; for example recommendations about communication and record-keeping may have been influenced by the greater throughput in hospital settings of people unwell with COVID-19.

The most frequently reported broad theme of recommendations was that of communication and record-keeping. Clusters of recommendations were made in relation to: communication between hospital teams and families and hospital teams and paid carers; the use of video to support communication between patients and their families/carers; the use of hospital passports to aid information-sharing; and ensuring that professionals are aware of services available to people with learning disabilities, including specialist learning disability services.

The second most frequently reported broad theme of recommendations was in relation to end of life care. The largest proportion of these were in relation to involving people with learning disabilities and their families and paid carers in DNACPR decisions; the full documentation of such decisions; and the timeliness of end of life care decisions. Other recommendations were about the provision of end of life care and ensuring that people and their families and carers are well-supported at the end of life.

The third most frequently reported broad theme of recommendations was in relation to training requirements. A wide variety of training needs were reported, most commonly general awareness raising about the needs of people with learning disabilities; training about Mental Capacity Act and Equalities Act requirements; training about recognising signs that a person was unwell and about the recognition of deterioration; and training about specific clinical issues including pneumonia, dysphagia, epilepsy, end of life care and annual health checks.

Access to, and involvement with specialist services was the fourth most frequently reported broad theme of recommendations. Here, the importance of access to learning disability liaison nurses in acute settings was frequently mentioned. Other specialist services mentioned included dieticians, dentists and epilepsy and dementia specialists.

<b>Table 12: Selection of broader recommendations made by reviewers</b>		
<b>Broad theme</b>	<b>Number of times mentioned</b>	<b>Examples of recommendations</b>
Communication and record-keeping	102	<p>'Care home staff need opportunity to ask hospital team about decisions when they are unclear'.</p> <p>'Guidelines should be developed to enable hospital staff in leadership positions to implement creative approaches to ensure patients and their relatives can communicate to promote their comfort and minimise ...distress'.</p> <p>'Medical staff should include care home staff in discussions in relation to the care and treatment of people with a learning disability if they have capacity to consent to this or if their families wish for them to be involved to support them'.</p> <p>'Full details of essential contacts must be available in a 'grab sheet' format to travel with an individual going to hospital'.</p> <p>'Hospital Passports should be recognised within routine clinical reporting and given equal value as a method of communicating the complex needs of people with learning disabilities'.</p> <p>'Provide information to GP practices concerning what community services are available for people with learning disabilities, thresholds for referral and referral pathways particularly in relation to direct access for carers'.</p>
End of life care	64	<p>'Managers must reinforce the message with hospital staff that DNACPR decision needs to include family member/carer wherever feasible'.</p> <p>'Care homes to consider ...DNACPR orders and clearly indicate the wishes of the individual in hospital transfer letters, and hospital passport/This is me documentation'.</p> <p>'ReSPECT is not well known enough and is still being completed when individuals are often too ill to be involved in the decision making for themselves...Greater promotion of the use of this tool should be undertaken by all agencies supporting individuals with a learning disability'.</p> <p>'For ReSPECT [form] to have a capacity form attached so that this is not overlooked'.</p> <p>'Clinicians...to document all attempts made, even if not successful, when involving [next of kin] in conversations'.</p>

		<p>'It is important that staffing levels are not fixed, and they are sufficient in later stages to ensure that individuals do not die alone'.</p> <p>'Review end of life provision in hospital for COVID-19 patients with learning disability to allow next of kin or carers to be present'.</p> <p>'Psychological and emotional support at the end of life should be available'.</p> <p>'Opportunities should be made for all staff involved in caring for a resident to have a platform for debrief, reflection and remembrance'.</p> <p>'A requirement for family members to be offered a consultation appointment 6 weeks after the unexpected death of a loved one. This would give families an opportunity to explore in more detail about circumstances leading to the death. It would also be a good time for parents to formulate any questions or concerns in the form of reflection and de-brief'.</p>
Training	57	<p>'Case studies of good multi-professional and cross-organisational working practices with positive outcomes should be disseminated as good practice examples for all health and social care staff working with people with learning disabilities'.</p> <p>'For hospital staff to have be offered training on learning disability'.</p> <p>'To explore further what learning disability training 999 call handlers have in relation to managing people with a learning disability when they are distressed'.</p> <p>'Training to be provided for clinical staff on the requirements of the Mental Capacity Act (2005) and the Equality Act (2010)'.</p> <p>'Further training for all staff on pneumonia...and the risk factors and preventative measures'.</p> <p>'Care managers to ensure that all support workers attend mandatory dysphagia training'.</p> <p>'A simple leaflet/flow chart on what to do if residents are unwell and when to seek medical attention to be produced and distributed to supported living sites'.</p> <p>'Robust advice and education to be provided...in settings supporting people with learning disabilities in recognising deteriorating health, seeking medical assessment during COVID pandemic and at other times'.</p>

		<p>'Care home provider/ manager should ensure that all staff are trained and know how to use the NEWS2 score'.</p> <p>'A plan needs to be developed with local authorities to ensure the availability of oxygen saturation equipment and training of staff to use this'.</p> <p>'Emphasis in training packages that acknowledging and using carer expertise improves care and outcomes for the person'.</p> <p>'Include in medical staff learning disability/safeguarding training that learning difficulty is not a medical diagnosis and therefore not to be included in cause of death'.</p> <p>'It would be useful for staff to participate in regular emergency situation simulation sessions. This would help prepare staff for when an emergency situation occurs'.</p>
Involvement of specialist services	45	<p>'All hospitals should have an acute liaison nurse to help ensure reasonable adjustments and support for people with learning disabilities'.</p> <p>'The availability of Acute Liaison Learning Disability Nurses in Acute Trusts has made a positive impact on the support available to individuals within hospital. The service needs to be extended to cover 24 hours, 7 days a week.'</p> <p>'GP's to refer all patients with learning disabilities with high BMIs to the learning disabilities dietician'.</p> <p>'Review the provision of psychological services to people with a learning disability'.</p> <p>'People with learning disabilities should be supported to access mainstream services, when this is not appropriate, specialist learning disability clinicians should ensure they consult with other specialists to ensure the person is receiving the most appropriate treatment'.</p>
Mental Capacity Act	39	<p>'Strengthen MCA assessment processes and documentation of decisions among care providers'.</p> <p>'Care home managers, psychiatric teams and GPs who support individuals with learning disabilities and mental ill health must consistently consider how fluctuating mental capacity may impact upon decision making'.</p> <p>'Ensure clear documentation of mental capacity assessments and best interest decision making in all care settings'.</p>

		'DOLS requests should be outcomed within the national time frame guidance and if they cannot be, updates should be provided to the organisation requesting the DOLS'.
Holistic, well-coordinated care	31	<p>'A trigger, such as identified concerns ...leading to a safeguarding review, could have prompted a multi-disciplinary team to take a holistic view of a change in care needs and if the care staff could adequately meet needs.'</p> <p>'Individuals with complex health needs should have regular multi-agency reviews'.</p> <p>'In complex cases, one professional needs to take overall responsibility for coordinating care and communicating / making decisions with all members of the multi-disciplinary team'.</p> <p>'A more holistic approach is needed in managing clients with recurrent chest infections'.</p> <p>'Multi-disciplinary team staff to anticipate the needs of the patient to ensure their voice is heard.'</p>
Hospital discharge	23	<p>'Hospital staff must liaise directly with responsible commissioner to ensure that on discharge the care package is both appropriate to need and legally funded.'</p> <p>'Early referral into community learning disability nursing who could support discharge planning.'</p> <p>'Care staff need to have clear guidance when a person is discharged from hospital'.</p> <p>'Better communication between the hospital discharge team and GP/Community Services'.</p> <p>'Put in place comprehensive discharge pathways for people with learning disability including access to rehabilitation'.</p>
Annual health checks and health action plans	21	<p>'The CCG should consider what support they can offer to GPs to ensure that all people with learning disabilities are offered an annual health check.'</p> <p>'Annual health check needs to note all health issues and their management and be linked to a health action plan'.</p> <p>'Ensure that GP practices use correct coding for patients with learning disabilities to ensure they are on the practice Learning Disability register and can therefore be easily identified'.</p> <p>'Social care needs of residents in residential care home placements should be reviewed annually'.</p>

Assessments and reviews of care	21	<p>'Where there have been multiple contacts with a patient, or carer on behalf of a patient, Call Handlers to ensure a clinician becomes involved'.</p> <p>'A pain/distress profile tool to be developed for all people ...where there is a difficulty with communication. This should involve everyone that knows the person well.'</p> <p>'Where a decision is reached that a patient does not require admission to hospital the individual with learning disabilities and their carers should be provided with Easy Read information about what to look for if the patient starts to deteriorate'.</p>
Systems/policy issues including staffing	18	<p>'The CCG should review the availability of wheelchair scales within their area to ensure that anyone requiring wheelchair scales is able to access them.'</p> <p>'Health services should consider reviewing their missed appointments policies to take into consideration adults who rely on others for support to attend appointments, and what processes they need in place to safeguard these individuals'.</p> <p>'Health services should review their appointments booking processes and ensure that they have a procedure in place for notifying carers/ support services when appointments are booked'.</p>
The provision of reasonable adjustments	16	<p>'Ensure we continue to think 'outside the box' for people with learning disabilities and not be forced down care pathways that are not moveable because "one size does not definitely fit all".'</p> <p>'A dynamic process for reviewing visiting is required when there is a rapidly changing situation to ensure that, as much as is possible, reasonable adjustments can be made'.</p>
Advocacy	7	<p>'The role of advocacy and empowerment in hospitals is crucial for patients with learning disabilities who may be additionally distressed by their environment, interventions and lack of familiar faces. The expertise of Learning Disability nurses, means that they are well placed to fulfil this role and to ensure that the voice of the patient with learning disabilities is heard.'</p>

## Appendix 1: Selection criteria for inclusion in this sample

### Background

Analysis of 200 deaths during the first wave of the 2020 COVID-19 pandemic was proposed to provide information to enable NHS England and the Department of Health and Social Care to identify service improvements in anticipation of a second wave of the virus in autumn 2020.

All of the deaths were reviewed using the established LeDeR programme methodology<sup>19</sup>, supplemented with a prompt sheet designed specifically for the review of deaths due to COVID-19.

### Sampling frame

The 200 notifications were selected on the basis of geographical region, COVID-19 diagnosis, and demographic characteristics.

#### Region:

- 40 from each of the four NHSE regions that had experienced the most deaths of people with learning disabilities from COVID-19 (London, Midlands, North West, South East).
- 40 spread evenly between the other three NHSE regions combined (East of England, North East & Yorkshire, South West).

#### COVID-19 status:

- 80% (n=160) of reviews to be of people **with** a confirmed or suspected diagnosis of COVID-19 at the time of their death.
- 20% (n=40) of reviews to be randomly selected from people **without** a confirmed or suspected diagnosis of COVID-19.

#### Demographic and other characteristics:

- Age: 20% aged 18-49 years; 80% aged 50 years and over.
- Gender: 60% male, 40% female.
- Ethnic group: 80% white British, 20% other ethnic groups.
- Place of death: 60% hospital, 40% other.

For each of the above categories, if there were insufficient deaths in a region to meet the minimum sampling threshold (e.g. only 10% of deaths were among 18-49 year olds) then all deaths in the category were included in the sample. Additional deaths meeting the requirement of a different category were then reviewed to maintain the sample size and regional distribution.

### Time frame

All deaths included in the sample occurred during a 100-day period between 02/03/2020 and 09/06/2020.

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<sup>19</sup> See: <http://www.bristol.ac.uk/sps/leder/about/detailed-review-process/>

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