



Fury at 'do not resuscitate' notices given to Covid patients with learning disabilities

Vulnerable people have encountered 'shocking discrimination' during pandemic, says Mencap charity

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People with learning disabilities have been given do not resuscitate orders during the second wave of the pandemic, in spite of widespread condemnation of the practice last year and an urgent investigation by the care watchdog.

Mencap said it had received reports in January from people with learning disabilities that they had been told they would not be resuscitated if they were taken ill with Covid-19.

The Care Quality Commission said in December that inappropriate Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) notices had caused potentially avoidable deaths last

year.

DNACPRs are usually made for people who are too frail to benefit from CPR, but Mencap said some seem to have been issued for people simply because they had a learning disability. The CQC is due to publish a report on the practice within weeks.

The disclosure comes as campaigners put growing pressure on ministers to reconsider a decision not to give people with learning disabilities priority for vaccinations. There is growing evidence that even those with a mild disability are more likely to die if they contract the coronavirus.

Although some people with learning disabilities such as Down's syndrome were in one of four groups set by the Joint Committee on Vaccination and Immunisation (JCVI) which the government promised would be offered the vaccine by tomorrow, many were classified lower categories of need and are still waiting.

NHS figures released last week show that in the five weeks since the third lockdown began, Covid-19 accounted for 65% of deaths of people with learning disabilities. Figures from the Office for National Statistics show that the rate for the general population was 39%, although the two statistics are drawn from different measurements.

Younger people with learning disabilities aged 18 to 34 are 30 times more likely to die of Covid than others the same age, according to Public Health England.

Edel Harris, Mencap's chief executive, said: "Throughout the pandemic many people with a learning disability have faced shocking discrimination and obstacles to accessing healthcare, with inappropriate Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) notices put on their files and cuts made to their social care support.

"It's unacceptable that within a group of people hit so hard by the pandemic, and who even before Covid died on average over 20 years younger than the general population, many are left feeling scared and wondering why they have been left out.

"The JCVI and government must act now to help save the lives of some of society's most vulnerable people by urgently prioritising all people with a learning disability for the vaccine."

More than 14m people have received a first vaccine dose so far, and care providers who spoke to the *Observer* said many people with learning disabilities had been vaccinated in the last week. But some are still waiting. One woman from the West Midlands who has a rare form of Down's syndrome told the *Observer* she had not yet been given a date.

"It's really frustrating - it's been a fight and it shouldn't have been a fight," she said. Her condition means she is in category four - people who are clinically extremely vulnerable - but her GP did not have details of her condition on record - a common problem, according to Mencap.

"I had to call them lots of times," she said. The practice accepted last week that she needed to be vaccinated, she said, but she was still waiting. "For people in a similar situation to me, they won't have been badgering them as much as me."

A lack of badgering is part of the reason why people with learning disabilities may be more likely to die from Covid-19 than the rest of the population, according to Dr Keri-Michèle Lodge, a consultant in learning disability psychiatry in Leeds.

“Doctors often don’t understand that someone with learning disabilities may not be able to communicate their symptoms,” she said. “Carers are sometimes not listened to - you might notice something is wrong, but that is often written off as part of their behaviour.

“People with learning disabilities already get a raw deal from the health services. Fewer than two in five people with a learning disability live until they are 65.”

An analysis by the Office for National Statistics last week showed that six in 10 Covid deaths were of people with a disability.

“The biggest factor associated with the increased rate of death from their analysis was living in care homes or residential settings,” Lodge said. “They prioritised people in care homes for vaccinations, but that was only for older adults. They completely forgot about people with learning disabilities in a really similar setting. I don’t know if the government were blindsided or just neglectful.”

Professor Martin Green OBE, Care England’s chief executive, said: “As the largest representative body for independent providers for adult social care, Care England remains concerned that the government has not given individuals with a learning disability a higher level of priority for the Covid vaccine.

“We urge the government to remove the arbitrary distinction between prioritising those with a severe or profound learning disability and those with a mild or moderate learning disability, and prioritise all those with a learning disability in priority group four. People with learning disabilities must not be overlooked at any time.”

. This article’s headline was amended on 13 February 2021 to remove an incorrect reference to “learning difficulties”.

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