

Doctors warned that learning disabilities or Down's no reason not to resuscitate patients

Rosamund Urwin

Doctors should never put a "do not resuscitate" order on a patient simply because they have learning difficulties, a leaked report recommends.

The annual report from the Learning Disabilities Mortality Review (LeDeR) programme, which has not yet been published but has been seen by The Sunday Times, reveals that 19 patients who later died had "learning

disabilities" or "Down's syndrome" given as the reason not to resuscitate them between July 2016 and December 2018.

The scale of the issue may be much bigger, however, as reviews into only a quarter of the 4,302 deaths reported to LeDeR had been completed by the end of last year.

LeDeR was set up in 2015 to help local authorities review the deaths of people with learning disabilities and

to identify where care could be improved.

The programme, run by Bristol University on behalf of NHS England, also found that 8% of adults with learning disabilities who had died had received care "that fell so short of good practice that it significantly impacted on their wellbeing or directly contributed to their cause of death".

According to the report, the median age of death for

people with learning disabilities – excluding those under the age of 4 – was 60 for men and 59 for women. This compares with a female life expectancy of 83 and male expectancy of 79 for the wider population, according to data from the Office for National Statistics.

The LeDeR programme has recently come under criticism. Paula McGowan, whose teenage son Oliver died in 2016, has called for

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the LeDeR process to be reformed and run by a "truly independent" body.

"LeDeR is not fit for purpose," she said.

"LeDeR is a tool to learn the lessons of the 1,200 preventable deaths of learning disabled people each year, but it should be taken out of the hands of NHS England with investigations conducted by an independent organisation." Oliver contracted

meningitis at the age of three weeks and later developed mild autism, epilepsy and learning difficulties.

Aged 18, he was taken to Bristol's Southmead Hospital in October 2016 after he suffered seizures.

"We were living this lovely, normal life and then Oliver was taken into hospital with a seizure and given medication he should never have had," said McGowan.

Oliver suffered oxygen

starvation after he was given the anti-psychotic drug olanzapine against his parents' wishes. He died in November 2016.

McGowan now campaigns to improve the treatment of patients with learning disabilities. "The public thinks that if you have a diagnosis of intellectual disability or autism, you will die early anyway," she said.

"That's not the case. We need to highlight that these

are treatable conditions and that [some patients] are dying because they're not getting the right healthcare."

NHS England said: "We expect nurses, doctors and other health and social care professionals to act on the findings of this report, the first of its kind the world. Nearly two-thirds of all cases have now been completed or are under way so that local services can drive improvements in treatment."