



NHSE estimates mortality rate for autistic people is 51pc higher

By Emily Townsend | 13 December 2022

Leaked NHSE document reveals estimated mortality rate for autistic people

People with autism dying five years earlier on average compared to general population

Inequality “utterly wrong in this day and age”, charities warn

Autistic people in England who do not also have a learning disability are approximately 51 per cent more likely to die in a single year compared to the general population, according to a leaked document which estimates the mortality rate for the first time.

According to an internal NHS England document, seen by *HSJ*, the standardised mortality rate between April 2020 and March 2021 was 16.6 deaths per 10,000 for people with autism and no learning disability compared to 11 deaths per 10,000 for the general population.

There is some uncertainty around the 16.6 figure, with lower and upper bounds of 13 and 20.6 given at 95 per cent probability (see table below).

NHSE also determined life expectancy for this group to be 75 years – 5.4 years less than the general population.

There have previously been studies and data on mortality and life expectancy for people with learning disabilities; for example NHS Digital calculated that from 2015-18, people with a learning disability were about four times more likely to die than the general population.

However, the NHSE analysis seen by *HSJ* states that it is the first time it has been possible to calculate mortality for autistic people on “something approaching” a national basis for England. It highlights that there is uncertainty and that gaps in the data remain, however.

Researchers also caveat the data as it applies to the first year of covid, which was a “very abnormal year for mortality rates”. It covers 56 per cent of GP registered patients in England.

Headline Statistics

Mortality in April 2020 to March 2021 (Part 1)



People with autism and a learning disability are more than twice as likely to die in a single year vs the general population (23.1 deaths per 10,000 vs 11 deaths per 10,000 people).

People with autism and no learning disability are approximately 51% more likely to die in a single year vs the general population (16.6 deaths per 10,000 vs 11 deaths per 10,000 people).

Directly standardised mortality rate

Population Category	Direct Standardised Rate (per 10,000)	Lower CI (95%)	Upper CI (95%)
General population	11.00	10.90	11.00
Autism no learning disability	16.60	13.00	20.60
Learning disability no autism	29.50	28.30	30.80
Autism with learning disability	23.10	18.60	28.10

NOTE: It is the first time it has been possible to publish mortality data relating to autistic people on something approaching a national basis for England. In reviewing them it is important to remember that the specific year (April 2020 to March 2021) was a very abnormal year for mortality rates as it included both the first and second major waves of the COVID-19 epidemic.

41 |

NHSE slide on mortality rates for people with a learning disability and autism

Public Health England analysis in 2020 found covid death rates for people with learning disabilities were three to six times greater than for the general population.

‘Overlooked’

Dominic Slowie, former national clinical director for learning disability, told *HSJ* that because of the different ways autism presents itself, it can be difficult to pinpoint causes of premature mortality.

“In some cases, people with autism who are severely disabled and can’t communicate their needs in a conventional way are going to have premature mortality for the same reasons that people with a learning disability do, because people do not really understand the level of their need or do not investigate their need in a reasonably adjusted way,” he said.

“While, if someone is presenting atypically in their communication, we mustn’t make presumptions – we must make reasonable adjustments to ensure they are investigated and diagnosed in the same way.”

Meanwhile, Tim Nicholls of the National Autistic Society said interpreting and letting doctors know symptoms can be difficult for autistic people.

He told *HSJ*: “The sensory environment of a GP surgery might feel impossible to cope with, autistic people may be over- or under-sensitive to pain, they might find public health information too confusing to follow, or they might be tired of trying to engage with a health system that doesn’t understand them.

“All these things contribute to the difficulties autistic people face when they’re trying to use the NHS and will be part of the reasoning behind this new evidence.”

The NHSE document also estimates the mortality rate for autistic people who also have a learning disability as being twice the rate of the general population between April 2020 and March 2021.

Dr Slowie said causes of premature mortality in this group would be “multifaceted” and may be driven by social factors such as isolation, unemployment, poor diet and nutrition, alongside less healthcare.

He added: “If people are marginalised and isolated, and a pandemic comes along, it increases their risk. Those social factors are likely major determinants... And a large number are likely to have been institutionalised.

Dominic Slowie

“It’s absolutely not a clear-cut scenario, but I think it’s important to recognise [societal values] are part of this. Those people who died at twice the rate... were people whose lives were not valued in the same way.

“There is an element of subconscious eugenics – that sounds quite melodramatic... but we’re doing it subconsciously a lot of the time, during covid, ministers and policymakers were either subconsciously, or consciously, overlooking this group in terms of risk.”

Government’s vaccination guidance did not include everyone on the learning disability register as clinically vulnerable until late February 2021, after some had already become critically ill.

Meanwhile, the Care Quality Commission said in December 2020 that inappropriate “do not resuscitate” notices had caused potentially avoidable deaths in the first covid wave.

Inequality ‘utterly wrong’

Additional data in the documents reveals autistic people are six times more likely to be prescribed antipsychotic medication than the general population, while people with a learning disability and autism are 21 times as likely.

And autistic people were approximately 14 per cent less likely than non-autistic people to receive breast cancer screening between 2016 and 2021.

Rates differ between integrated care systems, with just 30 per cent of autistic people receiving breast cancer screenings over five years in Black Country ICS, compared with 60 per cent in Buckinghamshire, Oxfordshire and Berkshire West ICS.

System-level figures are limited in scope due to some organisations submitting poor quality or no data; however, data coverage for the above ICSs is significantly above 45 per cent, and considered to be reasonably representative.

Mark Axcell, Black Country ICS CEO, said the organisation is working closely with providers to offer reasonable adjustments and encourage uptake.

The internal dataset is described as the “first step in drawing together statistical information currently available about the health... of autistic people in England, and about their levels of mortality and life expectancy”.

Mr Nicholls added: “It’s utterly wrong that in this day and age autistic people experience such inequality in our health system. Autistic people need the right support and professionals who understand autism, but these shocking figures show the devastating consequences when this doesn’t happen. It’s vital that the reasons are fully researched, understood and tackled.

“This is why commitments in the government’s autism strategy and NHSE’s long-term plan are so vital, and why they must be fully funded.”

Deaths review ‘must hold to account’

In the 2019 long-term plan, NHSE aimed to improve uptake of annual health checks for people with a learning disability to 75 per cent and to pilot the introduction of a specific health check for autistic people, which launched at 12 early adopter sites in 2021.

National levels of health checks for people with a learning disability were at 75 per cent for October. Meanwhile, under a third of people in hospital (550) had their health checked in the past six months, according to latest data.

Dr Slowie also led commissioning of LeDeR, which reviews deaths of people with a learning disability and from next year will also examine autistic people’s deaths.

He told *HSJ* LeDeR has so far been good at analysing why people are dying early, but it now needs to hold to account.

“That is where it gets a bit weak and wobbly,” he said. “It’s about how do we make sure these avoidable deaths don’t happen again, in a tangible, concrete way, with organisations held to account in a psychologically safe way — because if people think they’re going to get sacked, they won’t come forward with evidence.”

An NHSE spokesperson said: “These new figures serve as a vital reminder as to why improving health and wellbeing of autistic people and those with a learning disability is a priority for NHSE, highlighting the need to continue to help improve care and prevent potentially avoidable deaths of people with a learning disability.

“The NHS is still on target to meet the long-term plan commitment to provide three quarters of people with a learning disability aged 14 and over with an annual health check, and continue to work with partners across social care and local authorities to deliver lasting health improvements and reduce health inequalities enabling people to live longer and healthier lives.”

DHSC was asked to comment.

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