LeDeR Annual Report 2022

The annual Learning Disabilities Mortality Review (LeDeR) report was published yesterday. The LeDeR programme was established in 2017 to review the deaths of people with a learning disability and autistic people to find areas of learning, opportunities to improve, and examples of good practice. This year is the first time reports of deaths of autistic adults without a learning disability are included. NHS England (NHSE) has also published its Action from Learning Report 2022-23 which gives examples of local and national work to reduce health inequalities for people with a learning disability and autistic people as well as updates on the commitments NHSE made in last year's Action from Learning Report.

We summarise the two reports below and set out NHS Providers' view. If you have any comments on this, please contact Ella Fuller, senior policy advisor (ella.fuller@nhsproviders.org).

Key points

- The median age at death for people with a learning disability in 2022 was 62.9 years old. This is an increase from 2018 (61.8), despite the Covid-19 pandemic, showing a continuous improvement between 2018 and 2022. The median age at death for autistic adults with a learning disability was 55 years. However, the median age at death for these groups remains far lower than for the general population: in 2018-2020 it was 82.6 years for males and 86.1 years for females.
- People with a learning disability from all ethnic minority groups died at a younger age in comparison to people of white ethnicity (adjusting for other factors such as sex, region, deprivation, and place of death).
- Forty-two per cent of deaths were deemed "avoidable" for people with a learning disability. This is a reduction from 2021 (50% of adult deaths), however it remains significantly higher compared to 22% for the general population. Concerns with care were expressed in 25% of deaths in 2022, compared to 39% of deaths in 2021. Organisations' systems and processes were the most common area of problems with care reported by reviewers.
- Nine out of ten reviews included evidence of good practice, with themes including: an awareness of autism and efforts to make reasonable adjustments; timely communication between agencies providing care; and plans in place for crisis and escalation support where appropriate, including assessments of suicide risk.

- The report suggests several areas for future consideration by health systems and providers to reduce causes of death for people with a learning disability and autistic people. This includes improving Do Not Attempt CPR (DNACPR) completion and adherence and adapting health screening to ensure earlier detection of cardiovascular disease and cancer.
- Other examples to prevent and better manage avoidable and long-term conditions, particularly for adults aged 25 to 49, include continued prioritisation for and awareness of vaccinations, the provision of annual health checks, and improving care pathways of specific conditions such as cardiovascular disease and osteoporosis.

Findings from the LeDeR report

Key demographics

- Of the people with a learning disability who died in 2022: 55% were male, 45% were female; 94% were denoted as white, 3% were Asian or Asian British and 2% were Black, black British, Caribbean or African; 43% were denoted as Christian, 30% preferred not to say and 21% had no religion; and 25% lived in the most deprived neighbourhoods, compared to 10% in the least deprived.
- The Midlands had the highest percentage of deaths in 2022 LeDeR reviews (22%), followed by the South East (17%) and North East and Yorkshire (16%). The South West had the lowest (10%).

Causes and circumstances of death

- The five most common causes of death for adults with a learning disability were:
  - Circulatory system (16.7%) – compared to the combined percentages from 2018 and 2019 (15.8%).
  - Cancers (14.6%) – little change, although the percentage of deaths caused by bowel cancer and lung cancer is slightly higher in comparison to previous years.
  - Respiratory system (14.6%) – lower in 2022 in comparison to the combined percentage from 2018 and 2019 (20.7%).
  - Nervous system (13.6%) – higher than previous years
  - Congenital malformations and chromosomal abnormalities (13.3%) – similar to 2018 and 2019 (14.2%) but higher than 2020 and 2021 (10.1%)
- 25% of deaths were referred to a coroner, compared to 19% in 2020 and 2021, and 22% in 2018 and 2019. 36% of deaths in the general population in 2022 were referred to a coroner.
- 57% of deaths occurred in hospital, which is similar to previous years. A greater proportion of people with a learning disability die in hospital compared to the general population (45% in 2021).

- 74% of people had a DNACPR in place at the time of death. Reviewers judged this was correctly followed 63% of the time compared with 61% in 2021.

Areas for future consideration

1. Involving people and their families in DNACPR documentation could further improve completion and adherence by reducing incorrect recording and following of documentation.
2. Prioritise people with a learning disability for vaccination to help reduce the continued impact of Covid-19.
3. High risk groups should be targeted for screening of cardiovascular conditions, bowel cancer and lung cancer e.g., earlier screening ages may need to be considered.

Factors associated with age at death

- People with a learning disability from all ethnic minority groups died at a younger age in comparison to people of white ethnicity (adjusting for other factors such as sex, region, deprivation, and place of death).
- Epilepsy was the long-term condition that was most strongly associated with dying at a younger age. This was followed by deep vein thrombosis, and degenerative conditions.
- Those who did not die in hospital, or their usual place of residence were at increased risk of dying younger. This was also seen in last year's LeDeR report.

Areas for future consideration

- Appropriate care was associated with reductions in premature death e.g., care packages that meet a person's needs and appropriate use of Deprivation of Liberty safeguards.
- Use of appropriate medical treatment and prevention are associated with reductions in the risk of an earlier age at death, e.g., use of vaccines to protect against Covid-19 and pneumococcus, and use of mental health treatments (medications).

Avoidable mortality

Deaths for people with a learning disability were more likely to be classified as "avoidable" with increasing age, peaking in the 25 to 49 age group, before decreasing again for those who died over the age of 65 years. Men were found to be 22% more likely to die from an avoidable cause of death than women.

26.4% of avoidable deaths were linked to cardiovascular conditions, 23.8% to respiratory conditions (excluding Covid-19), and 15.7% to cancers.

Areas for future consideration

4 Prevention and better management of avoidable and long-term conditions in adults, particularly the age group 25-49. Care pathways of specific long-term conditions such as cardiovascular disease and osteoporosis could also be improved.
5 Addressing reasons for the increased risk of dying from an avoidable death in males compared to females.
6 Earlier interventions for preventable and avoidable causes of death may be necessary as they appear to increase around the age of 50 e.g., earlier screening ages, continued prioritisation for and awareness of vaccinations, and the provision of annual health checks.

Quality of care

Organisations' systems and processes were the most common area of problems with care reported by reviewers. Some of the emergent themes from the reviews included:

- A lack of high-quality training, awareness and understanding of autistic people's needs.
- A lack of adequate support services being provided, specifically tailored towards the needs of the person, or a lack of support to access services.
- Overlooking the potential impact of a relationship status change for autistic adults.
- A lack of crisis escalation plans or awareness of increased risk of suicide in autistic adults.
- A lack of communication between different professionals and agencies providing support.
- Overshadowing of the impact of autism by other co-occurring mental health conditions.

However, nine out of ten reviews included evidence of good practice. Some of the emergent themes were: an awareness of autism and efforts to make reasonable adjustments; timely communication between agencies providing care; and plans in place for crisis and escalation supports where appropriate, including assessments of suicide risk.

Areas for future consideration

7 Supporting staff in in primary care to make the best use of existing guidance and resources, or better IT solutions, to maintain the learning disability register.
8 Training or support to ensure all staff apply the Mental Capacity Act correctly.

9 Ensuring people with a learning disability who have multiple long-term conditions receive an individualised management plan and utilising mechanisms to co-ordinate care for people who are involved with different health professionals.

Excess deaths, Covid-19, and climate

In every month of 2022 except January, deaths were in excess of what would be expected. However, since LeDeR notification is not mandatory it is difficult to distinguish whether this is down to a larger number of deaths or due to an increase in awareness of the requirement to report and conceivable it is a combination of both.

July recorded the highest number of notifications of deaths in 2022, 13% of which occurred on 19 and 20 July. There was a record high temperature of 40.3°C in England on 19 July and the spike in deaths appears to be linked to the extreme heat.

The percentage of deaths caused by Covid-19 was still higher in people with a learning disability (5.7%) in comparison to the general population (3.9%). However, Covid-19 has decreased from 24% of all causes of death in 2020, to 19% in 2021 and 6% in 2022. It has gone from the most common cause of death to the 6th most common.

Areas for future consideration

10 Healthcare providers should continue to incorporate concerns regarding climate change into their policy and planning.
11 Consider how to ensure adequate hydration and access to temperature control such as air conditioning or fans. In the winter and colder months, consideration should be made for how to enable access to adequate heating and insulation.
12 Ensure care plans for people with a learning disability include mitigations and advice for dealing with hot and cold weather and provide this information in accessible ways.
13 Improve the collection of data on marginalised and vulnerable people.

Review of deaths of autistic adults

2022 was the first year LeDeR reviewed deaths of autistic adults without a learning disability. The number of reviews was small (36) and not representative, so only limited conclusions can be drawn. Increased reporting is needed to be able to determine areas for improvement. As awareness grows around the need to collect these data to better target services, identify areas where care can be

improved and guide policy, the number of deaths of autistic adults reported to LeDeR is likely to increase.

91% of **autistic adults without a learning disability** were denoted as white; 81% were male and 19% female; and suicide, misadventure or accidental death was the most frequent underlying cause of death. 84% of **autistic adults with a learning disability** were denoted as white; 68% were male and 30% were female; and respiratory conditions were the most frequent underlying cause of death (excluding "other"). It is notable that death by suicide is not as apparent in the sample of autistic adults with a learning disability.

Areas for future consideration

14 Awareness of the specific needs and consideration of autistic adults with a learning disability (which differ from those of autistic adults without a learning disability) and factoring in individual's specific needs in care plans, should continue to be a priority.

NHS England's Action from Learning Report

This year's Action from Learning report gives a range of examples of local and national work in addition to updates on the commitments NHSE made in last year's report.

Examples of good practice include:

- Cambridgeshire and Peterborough ICS working to improve access to talking therapies;
- Leeds Teaching Hospitals NHS Trust working to make its emergency department more accessible via the use of care bags; and
- Cheshire and Wirral Partnership NHS Foundation Trust delivering training to help staff proactively identify individuals at risk of premature mortality or preventable death.

NHSE has developed a new online LeDeR Resource Bank for health and care staff which includes resources on tackling health inequalities and resources on specific conditions, end of life care and identifying deterioration. The report also highlights the LeDeR data tool, which was launched in April 2023 and enables NHSE and ICBs to access the latest LeDeR review data and help inform local population health plans.

The report also highlights that ICBs are responsible for ensuring they address any learning from LeDeR reviews and improve the quality of services for people with a learning disability to reduce health inequalities and premature mortality. ICBs must have an executive lead for population groups

including people with a learning disability and autistic people of all ages, and people of all ages with Down's syndrome.

NHS Providers View

We welcome the renewed focus the latest LeDeR report brings to the inequalities that people with learning disabilities and autistic people continue to experience, as well as the ongoing need to improve the care and support available to them. Although there have been some improvements in 2022 compared to previous years, there remain too many people who are not receiving the care they should be able to expect from the health and care system.

Trusts recognise the importance of making adjustments to meet the needs of people with learning disabilities and autistic people, and ensuring an individual's needs are picked up early within every care setting. They are also concerned to ensure appropriate care and support in the right setting as close to home as possible, with care delivered by staff with the experience and skills required to fully meet individuals' needs. Trusts would welcome national support in this ongoing work.

The LeDeR report and NHSE's accompany Action from Learning report includes helpful areas for future consideration and examples of good practice for trusts and their wider partners. The health and care sector must continue to work together to provide a more joined-up approach for people with learning disabilities to ensure that disparities are reduced over time.