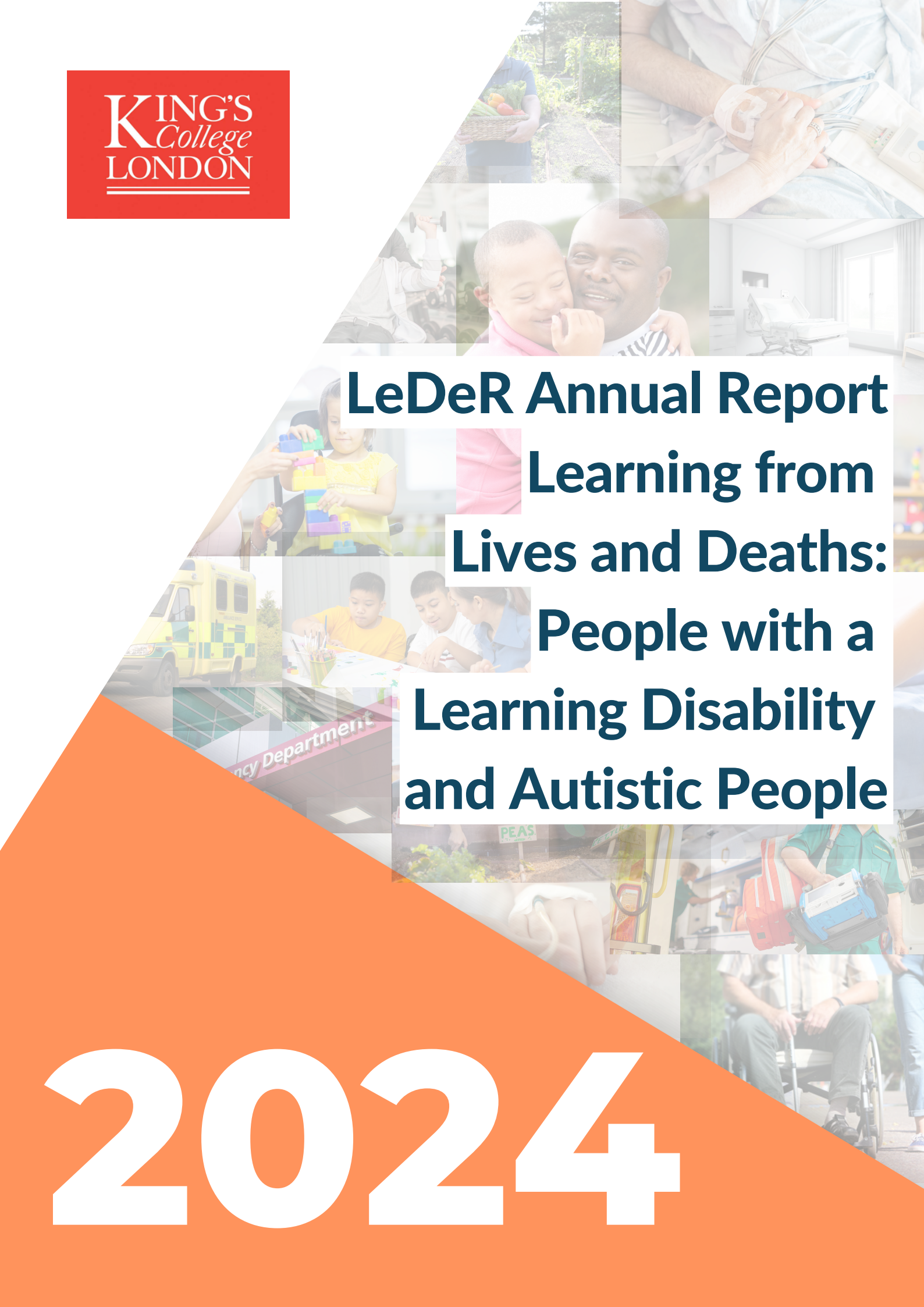

LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People

2024

LeDeR
Learning from lives and deaths – People with a learning disability and autistic people


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Learning from Lives and Deaths –
People with a learning disability and autistic people (LeDeR) report for 2024.
LeDeR Autism and Learning Disability partnership,
King's College London

Please be aware that this report discusses deaths, inequalities in care, and experiences of health and social care that some readers may find upsetting or distressing. The findings may be particularly difficult for people with a learning disability, autistic people, family members, carers, bereaved relatives, and professionals supporting individuals with complex health needs. The report also includes discussions of deaths by suicide and avoidable deaths.

If you or someone you know is affected by the content of this report, support is available. You can contact Samaritans free of charge on 116 123 (UK and ROI), email jo@samaritans.org, or visit samaritans.org to find your nearest branch. Other mental health and wellbeing support services, including support for carers and bereavement, are available through the NHS mental health support webpages and the NHS help for suicidal thoughts webpage. Support is available 24 hours a day, every day of the year, for anyone struggling to cope or needing someone to talk to.

Acknowledgements

These images are entrants to the Staying Alive and Well logo competition. 1. Tamsin, Milton Keynes, 2. Stacey, Wandsworth, 3. Peter, GRASSroots, 4. Louise, Darlington, 5. Charlie, Southwark, 6. Tunbridge and Tonbridge Wells day services.

We dedicate this report to the people for whom it is created: people with a learning disability and autistic people, their families, friends, colleagues, carers, and all staff and service providers whose lives are touched by this work, and hope that it will serve as a legacy to the people whose lives and deaths it reflects.

Working with people with a learning disability is a central and essential part of LeDeR. The Staying Alive and Well group of people with a learning disability have helped to shape the report and ensure that the findings of this report reach those who need them most. As one group member, Richard, reminds us: "We want to be seen and heard, our lives really do matter." Their dedication and advocacy for positive changes to services for people with a learning disability are inspirational. In addition, the Estia Centre at South London and the Maudsley NHS Foundation Trust, the Foundation for People with Learning Disabilities at London South Bank University, Learning Disability Partnership Board - East Sussex, and Pathways Associates have provided invaluable assistance in developing the accessible version of this report.

We would like to thank the many organisations and individuals who have made this report possible. We are grateful to the learning disability and autism team at NHS England for their support and oversight of the LeDeR programme; the team at South Central and West Commissioning Support Unit (SCW) for processing and managing the LeDeR data, the many individuals, families, health and social care professionals, and organisations across England who have contributed to the notification of deaths of people with a learning disability and autistic people; and the Integrated Care Boards (ICBs) whose staff have carried out the reviews. We also wish to acknowledge and thank bereaved families and carers who contributed to LeDeR reviews by sharing their experiences and reflections following the death of a relative or person they supported. We recognise that participating in a review can be emotionally difficult, and we are deeply grateful for the valuable insight and learning their contributions provide. We also wish to thank our technical colleagues at King's College London (KCL) for their expertise and support with data extraction and storage. We are grateful for the engagement and insight provided by our wider stakeholder community across the NHS and beyond, and to our independent advisory board, chaired by Professor Yona Lunsky of the University of Toronto, Canada, with members Carol Boys, Julian Hallett, Rhidian Hughes, Sam Potterson, and Jacqui Shurlock, whose expert guidance continues to strengthen this work.

Contents

Updates to the report - 2024

We have made some changes to the format of the 2024 annual report based on feedback received through consultation and from stakeholders, such as the advice of the independent advisory group and discussions with NHS England. A summary of these changes is given below.

- Addition of a chapter comparing mortality data between adults with Down syndrome and other adults with a learning disability
- Increased use of statistical analyses, including formal testing of differences between groups and over time, and modelling to assess trends
- Reporting of additional variables from LeDeR reviews, such as age at death by place of death, place of residence at death and co-occurring conditions
- Increased granularity of the place of death variable, with additional categories providing a more detailed classification of place of death.
- A structured analysis of qualitative free text data relating to problems with care

Changes have also been made to the format of the accessible report to ensure that it is more suited to a wider range of people.

- Development of a shorter, easy-read document without numbers, and a longer, easy-read document with numbers to allow for different communication needs

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LeDeR Report 2024

Introduction and Foreword

Foreword from the Staying Alive and Well Group

Far too many people with a learning disability are still dying too young. Why is this not headline news?

We are the Staying Alive and Well group. We are people with a learning disability who have helped with the LeDeR report. We think about what is in the report, and we help to make it easier to understand. Our voices are important because we have a learning disability, we live it, we know it. The numbers in this report are not just numbers for us. This is very real to us. This is about people. People dying too young: that could be us. Our voices are important because we need to speak up for people who can't speak up for themselves. We can help everyone to understand what it's like to have a learning disability, and what you need to do to support us well. Our voices are important because we can tell people what it's like not to have the same support and care as everyone else. Sometimes we are discriminated against or not taken seriously. That makes us angry and upset.

We have worked on the LeDeR report for almost five years now, making accessible versions of the report for people with a learning disability. We are still shocked that we haven't moved on that much. Every year, working on the report is difficult. It makes us think about our own lives and about our friends. It's scary to think what might happen to us. We explained our feelings in last year's foreword and the year before. Our feelings haven't changed.

LeDeR is important because it finds out exactly how much earlier people with a learning disability and autistic people died. It finds out what was the most common thing people died of, and if it could have been avoided. LeDeR is important because if we have those numbers, we may be able to learn from it and do something. LeDeR is important because it shows us that we have to change the way people with a learning disability are treated.

In this year's report, we read that people with a learning disability died 19 years younger. It's a big shocking gap. Everyone should read this report because it can open your eyes to the problems we are still in. Everyone with a learning disability is different. This year's report has chapters about different kinds of learning disability, like people with Down syndrome or people with mild or profound disabilities. This helps us to see if people need different kinds of help and attention. For example, we found that people with a mild learning disability (like us) need more help to live a healthy life. Otherwise, they might die of something that could be avoided, like a heart attack. For people who can't communicate with words, it's extra important to get the right support in hospital, so the nurses and doctors can understand what they need.

There are a lot of people involved in our lives, and everyone should have the chance to read this and make a difference. Especially if you are:

- Someone who supports people with a learning disability or autism like families and carers
- A manager of services, like the NHS
- In the government
- A doctor or nurse or other healthcare worker

Don't stop looking at this because that puts us back in the dark. Don't look away however uncomfortable it makes you feel. It may seem like we're not getting anywhere but we want you to keep reporting and reviewing the deaths of people with a learning disability. Our lives matter. Please listen, and then DO something!

Foreword from Prof. Andre Strydom

LeDeR remains the only mortality dataset worldwide that is uniquely focused on identifying improvements that should be made to reduce health inequalities and early deaths for people with a learning disability and autistic people. Since 2021, an academic partnership led by King's College London, including the University of Lancashire and Kingston University, has had responsibility for independent analysis of the LeDeR data and for publishing the national reports. This is the last year we are commissioned to undertake this task, and this report about people who died in 2024 will be our final report.

As in previous years, we acknowledge the limitations of the LeDeR dataset. Firstly, as it is a mortality dataset, we cannot estimate life expectancy or the number and nature of subgroups of individuals currently living in the community. A second limitation is that notification of deaths to LeDeR is not compulsory, and data on deaths may therefore be incomplete, though we believe the majority of deaths of people with a learning disability who access services are being notified. In contrast, notifications and reviews of the deaths of autistic people are likely not representative of the overall number of deaths, and caution is therefore necessary when interpreting the findings in Chapter 4. In addition, there are natural delays in completing reviews, such as when a death has been referred to a coroner. As in previous reports, to ensure these deaths are ultimately included in our reports, we have added all available data from completed reviews when making comparisons with previous years. This means that the number of deaths included may vary between annual reports as more reviews are added.

Details on the LeDeR review methodology can be found in Appendix 0.3.

In discussion with NHS England, it was decided to shorten the main report so that the focus is on key findings, with underlying detail included in the appendices. To make comparisons across years, we include the deaths of adults with a learning disability and autistic adults between 2021 and 2024, which were reviewed by LeDeR using the new reporting format that was introduced in June 2021.

We are continuing a focus on people who died and had a severe or profound learning disability (Chapter 2), as well as a chapter on deaths of people with Down syndrome (Chapter 3). Chapter 4 focuses on the deaths of autistic people who did not have a learning disability (Chapter 4). Finally, in Chapter 5, we have summarised the work we have been doing with NHS England on specific topics, known as "deep dives".

Despite its limitations, LeDeR continues to have a high profile, with a crucial impact on NHS England's ongoing efforts to improve services for people with a learning disability and autistic people, and delivering new insights that inform decision-making. Our stakeholders are clear that the annual LeDeR national reports have helped to drive advocacy, informed policy decisions, and provided the data necessary for service improvements. Where possible, we have therefore made clear suggestions for actionable interventions based on findings of the 2024 report, and it is our hope that funding for national collation of deaths notified through the reporting system with independent analysis and regular reports will remain an NHS priority.

Chapter 1

Review of Lives and Deaths of Adults with a Learning Disability

Introduction

Information included in this chapter

Chapter 1 draws on both LeDeR notifications, initial and focused reviews (Appendix 0.1 and 0.3), to provide a national overview of the characteristics, causes of death, circumstances of death and care experiences of adults with a learning disability whose deaths between 2021 and 2024 were notified to LeDeR. Further detail of the analyses is presented in the Research methods section.

The first part of this chapter summarises data from 13,218 notifications for adults with a learning disability who died between January 2021 and December 2024, and whose deaths were notified to LeDeR. The second part of this chapter presents findings from LeDeR reviews completed between June 2021 and November 2025. In total, 11,687 initial reviews were included for adults with a learning disability who died between January 2021 and December 2024, of which 3,164 also had a focused review.

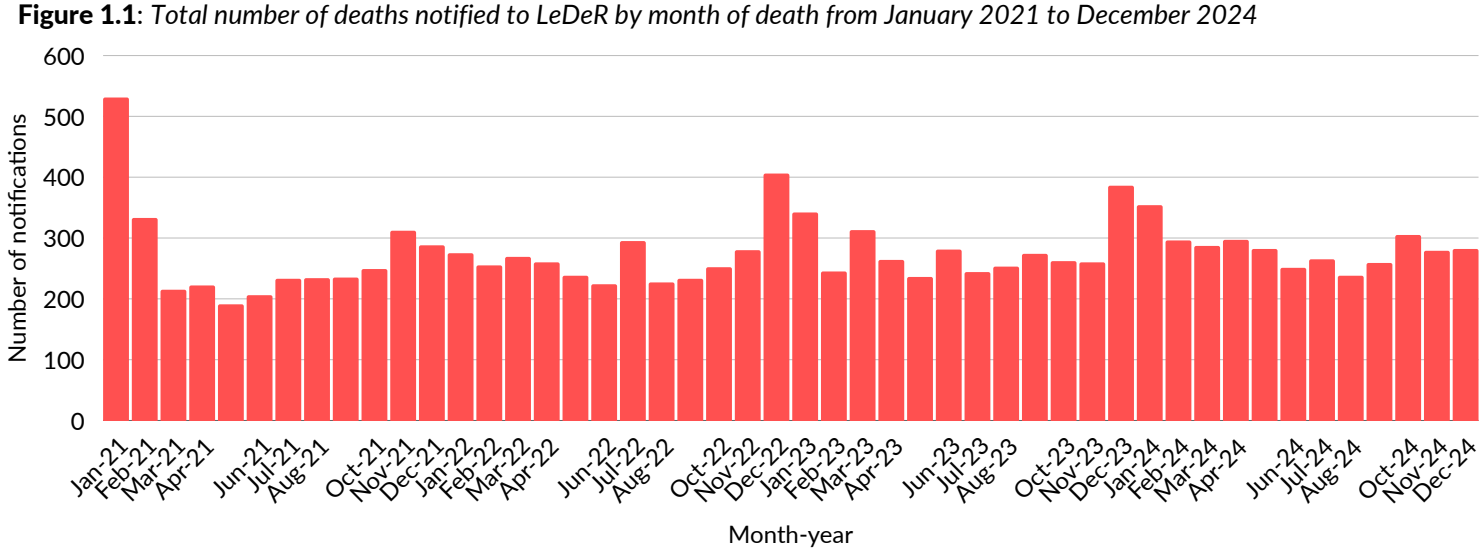
The notification and review analyses cover different time periods because notifications and reviews occur at different stages of the LeDeR process. Notification data are available as soon as a death is reported to LeDeR. In contrast, reviews are undertaken after notification and can take several months to complete, particularly where additional information is required from multiple services, or where a more detailed, focused review is undertaken. To ensure that sufficient time was available for reviews to be completed, the review analyses include deaths that occurred between January 2021 and December 2024, with reviews completed up to November 2025.

NHS England informed us that the difference in notification numbers compared with previous reports is due to the following reasons: In any given year, some deaths are notified to LeDeR relating to people who do not have a learning disability or a clinical diagnosis of autism. These deaths are not reviewed, and the notification data are deleted from the system. A decision was made by NHS England to remove the notification data relating to people who were not eligible for a LeDeR review (i.e. people who do not have a learning disability or a clinical diagnosis of autism, or who had not died), to protect their confidentiality and privacy rights. As a result, the number of notifications reported in the 2024 report is lower than in previous years' reports.

LeDeR Notification Data

Figure 1.1 shows the total number of deaths of adults with a learning disability notified to LeDeR by month of death from January 2021 to December 2024. The annual number of LeDeR notifications from 2021 to 2024 included in this report was 3,249, 3,214, 3,360, and 3,395, respectively. There are four notable spikes in the numbers of deaths notified to LeDeR across the period covered in Figure 1.1. The first, in January 2021, relates to a winter wave of COVID-19 and is also evident in national data from the general population (ONS, 2023). The second spike, in July 2022, relates to an extreme heatwave in England (UK Health Security Agency, 2024a), which is discussed in more detail in the LeDeR 2022 report (White et al., 2023). The third and fourth spikes in December 2022 to January 2023, and December 2023 to January 2024, may be attributed to seasonal respiratory infections including influenza and COVID-19 (UK Health Security Agency, 2024b). Similar spikes were also noted in the general population (ONS, 2025a).

Figure 1.1: *Total number of deaths notified to LeDeR by month of death from January 2021 to December 2024*



Demographics

Table 1.1 summarises the demographic characteristics of the 3,395 adults with a learning disability who died in 2024 and were notified to LeDeR, compared with those who died in 2021, 2022, and 2023, as well as the general population. As in previous years, most notifications were submitted by health and social care professionals, indicating continued professional engagement with the LeDeR process. For further information on the notifier relationship, see Appendix 1.3.

Table 1.1: *Demographics of adults with a learning disability*

Demographic	2021	2022	2023	2024	General adult population 2024
Sex registered at birth					
Female	1,339 (41.2%)	1,373 (42.7%)	1,282 (38.2%)	1,355 (39.9%)	259,354 (49.1%)
Male	1,748 (53.8%)	1,651 (51.4%)	1,779 (52.9%)	1,804 (53.1%)	268,393 (50.9%)
Not known	162 (5.0%)	190 (5.9%)	299 (8.9%)	236 (7.0%)	0 (0.0%)
Total	3,249 (100.0%)	3,214 (100.0%)	3,360 (100.0%)	3,395 (100.0%)	527,747 (100.0%)
Ethnic group**					
Asian or Asian British	68 (2.1%)	114 (3.5%)	95 (2.8%)	119 (3.5%)	±
Black African, Caribbean, or Black British	50 (1.5%)	61 (1.9%)	64 (1.9%)	56 (1.6%)	±
Mixed ethnic group	65 (2.0%)	16 (0.5%)	21 (0.6%)	20 (0.6%)	±
Other ethnic group	45 (1.4%)	*	20 (0.6%)	23 (0.7%)	±
White	2,720 (83.7%)	2,700 (84.0%)	2,834 (84.3%)	2,896 (85.3%)	±
They preferred not to say	150 (4.6%)	307 (9.6%)	326 (9.7%)	281 (8.3%)	±
Not known**	151 (4.6%)	*	N/A	N/A	±
Total	3,249 (100.0%)	3,214 (100.0%)	3,360 (100.0%)	3,395 (100.0%)	±
Region					
London	315 (9.7%)	323 (10.0%)	343 (10.2%)	388 (11.4%)	49,962 (9.5%)
South West	332 (10.2%)	327 (10.2%)	*	374 (11.0%)	60,977 (11.6%)
South East	534 (16.4%)	513 (16.0%)	541 (16.1%)	567 (16.7%)	86,885 (16.5%)
Midlands	656 (20.2%)	645 (20.1%)	666 (19.8%)	672 (19.8%)	107,829 (20.4%)
East of England	409 (12.6%)	348 (10.8%)	388 (11.5%)	363 (10.7%)	60,368 (11.4%)
North West	459 (14.1%)	494 (15.4%)	503 (15.0%)	453 (13.3%)	76,170 (14.4%)
North East and Yorkshire	539 (16.6%)	564 (17.5%)	595 (17.7%)	578 (17.0%)	85,556 (16.2%)
Not known	5 (0.2%)	0 (0.0%)	*	0 (0.0%)	0 (0.0%)
Total	3,249 (100.0%)	3,214 (100.0%)	3,360 (100.0%)	3,395 (100.0%)	527,747 (100.0%)

*Fewer than five. ** Due to changes in the LeDeR review process, data from 2023 onwards are not comparable with previous years. In particular, 'not known' was no longer available as a response option from 2023 onwards. For more information, see Appendix 0.4. ± Data not available from the Office for National Statistics.

Age at death

The age at death distribution of adults with a learning disability differed significantly ($p<0.001$) from that of the general population, with higher proportions of deaths in all age groups under 65 (Figure 1.2). Although the proportion of deaths aged 65 or over in 2024 increased slightly from previous years (Appendix 1.2 shows the proportions across all years), it remains much lower than in the general population (85.1%).

Figure 1.2: *Age group at death for adults with a learning disability compared with the general population*

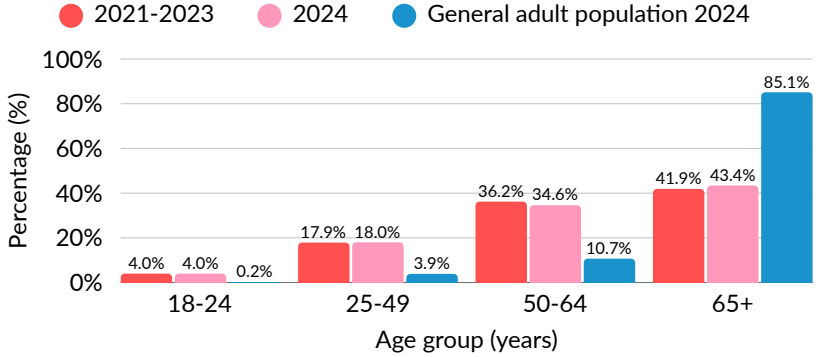


Table 1.2 shows the median age at death for adults with a learning disability whose deaths were notified to LeDeR between 2021 and 2024, with comparisons to the general adult population where possible. In 2024, the median age at death for all adults with a learning disability was 62.8 years, a small increase from 2021 (62.3 years); however, this remained substantially lower than the general population median age at death (81.8 years).

Table 1.2 also shows that median age at death was similar for males and females in each year and remained consistent from 2021 to 2024.

Median age at death by ethnic group was analysed according to the harmonised list of ethnic groups used in LeDeR (see Appendix 1.3). Across 2021–2024, the lowest median ages at death were seen for "Asian or Asian British" adults, and overall, adults in ethnic groups other than "White" had lower median ages at death, with considerable variation between groups. These findings should be interpreted with caution due to the smaller numbers of deaths reported for adults in ethnic groups other than "White".

Table 1.2: *Median age at death for adults with a learning disability*

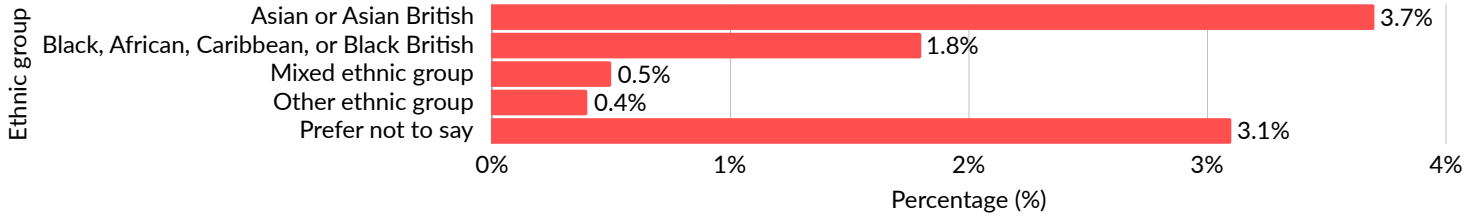
	2021	2022	2023	2024	General adult population 2024
Median age at death (IQR)					
All adults with a learning disability	62.3 (52.5 – 71.8)	62.2 (51.5 – 71.9)	62.3 (52.3 – 71.7)	62.8 (52.2 – 72.6)	81.8 (72.1 – 89.1)
Median age at death by sex (IQR)					
Female	62.3 (52.8 – 71.9)	61.7 (51.0 – 72.4)	62.4 (52.3 – 72.1)	62.6 (52.1 – 72.9)	84.1 (75.1 – 91.1)
Male	62.2 (52.0 – 71.7)	62.5 (52.5 – 71.6)	62.3 (52.3 – 71.5)	63.2 (52.8 – 72.4)	79.7 (69.9 – 87.3)
Median age at death by ethnic group (IQR)					
Asian or Asian British	40.7 (26.4 – 60.2)	42.5 (26.0 – 55.1)	44.0 (27.0 – 54.8)	41.9 (24.4 – 58.1)	±
Black African, Caribbean, or Black British	52.5 (32.6 – 57.7)	54.3 (28.9 – 59.4)	54.4 (36.7 – 60.0)	52.5 (37.6 – 62.0)	±
Mixed ethnic group	47.7 (32.6 – 59.2)	45.2 (26.5 – 67.8)	58.6 (40.1 – 67.4)	37.5 (22.9 – 58.1)	±
Other ethnic group	52.6 (34.6 – 63.9)	41.2 (33.0 – 60.6)	58.9 (41.7 – 75.8)	62.1 (45.0 – 69.2)	±
They preferred not to say	63.9 (48.4 – 72.2)	62.0 (49.5 – 71.6)	60.2 (48.3 – 70.7)	62.6 (50.2 – 72.8)	±
Not known	62.3 (53.4 – 72.3)	-	-	-	±
White	63.1 (53.9 – 72.3)	63.0 (53.4 – 72.5)	63.2 (53.8 – 72.2)	63.6 (54.2 – 73.1)	±

Data are presented as median age at death (interquartile range)
± Data not available from the Office for National Statistics

Of the 3,395 deaths notified to LeDeR in 2024, 2,713 LeDeR reviews were completed by November 2025. Of these, 1,989 (73.3%) were initial reviews and 724 (26.7%) were focused reviews. See Appendix 0.1 for a more detailed explanation.

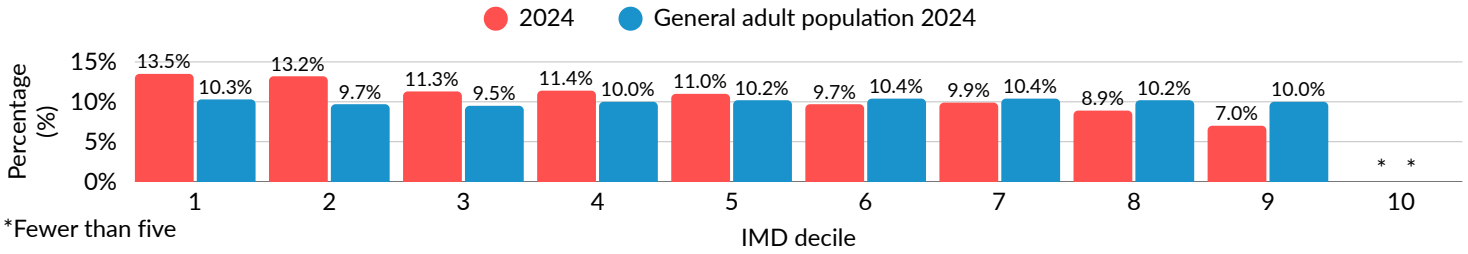
A higher proportion of deaths were among those registered male at birth (54.9%) in contrast to the general population where females account for a slightly higher proportion of deaths (p<0.001). See Appendices 1.4–1.5 for detailed breakdown of demographics. Most deaths of adults with a learning disability were from a "White" ethnic background. Adults from all other ethnic minority groups accounted for 9.5% of the reviews in 2024, an increase from 7.0% in 2023. Figure 1.3 shows the proportion of reviews relating to adults from ethnic minority groups other than "White".

Figure 1.3: *Ethnic minority group of adults whose deaths in 2024 were reviewed*



The distribution of Index of multiple deprivation (IMD) deciles is shown in Figure 1.4. A significantly greater proportion of adults with a learning disability who died in 2024 lived in the most deprived areas (IMD deciles 1 and 2; 26.7%) compared with the general population (20.0%, p<0.001).

Figure 1.4: *Index of multiple deprivation of adults whose deaths in 2024 were reviewed*



*Fewer than five

Circumstance at death

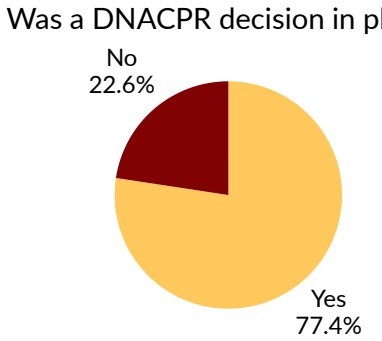
This section describes the circumstances surrounding the deaths of adults with a learning disability. In 2024, most deaths occurred in acute hospitals (54.2%), a slight decrease from previous years, and higher than in the general adult population (42.0%; Table 1.3). From 2021 to 2024, the distribution of place of death changed significantly (p<0.001). The largest changes were a decrease in deaths at home (-5.1%) and an increase in deaths in residential nursing homes (+5.3%), both lower than in the general population (18.4% vs 28.2%; 18.4% vs 21.8%, respectively). Overall, the 2024 distribution differed significantly from the general population (p<0.001), with more deaths in hospital and fewer at home and in hospices.

Table 1.3: *Place of death of adults with a learning disability*

Place of death	2021	2022	2023	2024	General adult population 2024
Acute hospital	1,583 (57.6%)	1,780 (56.4%)	1,690 (55.0%)	1,471 (54.2%)	221,050 (42.0%)
Assessment and treatment unit	*	*	6 (0.2%)	*	
Community hospital	43 (1.6%)	70 (2.2%)	82 (2.7%)	75 (2.8%)	
Home of the person who died	646 (23.5%)	575 (18.2%)	569 (18.5%)	500 (18.4%)	148,517 (28.2%)
Home of a friend or relative	14 (0.5%)	16 (0.5%)	18 (0.6%)	16 (0.6%)	
Residential nursing home	362 (13.2%)	559 (17.7%)	546 (17.8%)	500 (18.4%)	114,524 (21.8%)
Hospice	53 (1.9%)	53 (1.7%)	85 (2.8%)	71 (2.6%)	29,067 (5.5%)
Other	29 (1.1%)	89 (2.8%)	70 (2.3%)	68 (2.5%)	12,905 (2.5%)
Prison	0 (0.0%)	0 (0.0%)	0 (0.0%)	*	
Secure unit	*	*	*	0 (0.0%)	
Not known	15 (0.5%)	6 (0.2%)	*	9 (0.3%)	0 (0.0%)
Total	2,749 (100.0%)	3,154 (100.0%)	3,071 (100.0%)	2,713 (100.0%)	526,063 (100.0%)

Initial reviews show that between 2021 and 2024, the proportion of adults with a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision recorded at death increased significantly, rising from 72.2% to 77.4% (p<0.001), with the most noticeable increase in the most recent year. In contrast, there was no clear change over time in how often DNACPR decisions were correctly completed and followed (p=0.52), which remained at around two-thirds of cases. For a more detailed breakdown on DNACPR decisions, see Appendix 1.6.

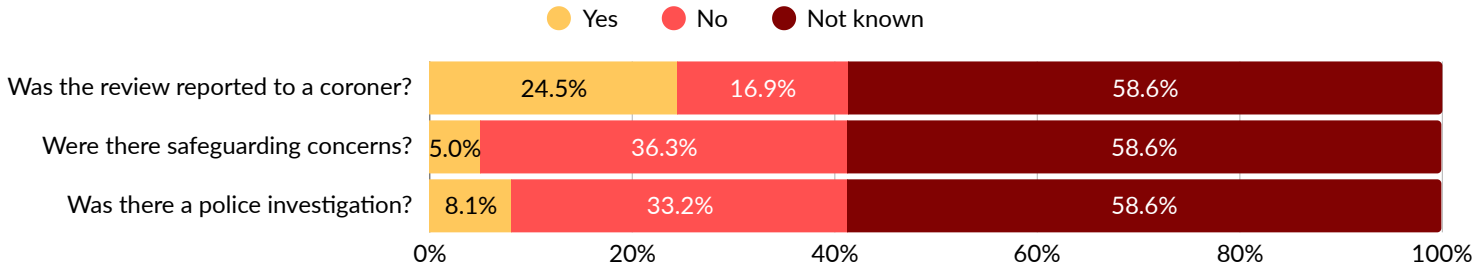
Figure 1.5: *DNACPR decisions for LeDeR review 2024*



Initial reviews also show that the proportions of deaths involving coroner referral, police investigation, and safeguarding concerns also differed significantly between 2021 and 2024 (all p<0.001). In 2024, 24.5% of deaths were reported to a coroner, a slightly lower proportion than in 2023 (28.0%), and the proportion of deaths with police investigations has also decreased (Figure 1.6).

Safeguarding concerns were lowest in 2024 (5.0%). For context, the most recent available safeguarding data for the general adult population (ONS, 2025b) indicates that approximately 1.4% of adults had a recorded safeguarding concern raised. This suggests that safeguarding concerns may have been more commonly identified in adults with a learning disability whose deaths were reviewed by LeDeR in 2024. For a more detailed breakdown of the circumstances at death, please see Appendices 1.6–1.7.

Figure 1.6: *Deaths reported to a coroner, police investigations, and safeguarding concerns for LeDeR review 2024*



Circumstance prior to death

From 2021 to 2024, the most common places of residence for adults with a learning disability who received a LeDeR review were residential nursing homes, family homes, and supported living tenancies (38.4%, 26.7%, and 22.5%, respectively; see Appendix 1.8). Adults living in a family home had the lowest median age at death (39.7 years), while those in a residential nursing home had the highest (62.1 years). These findings should be interpreted with caution as they are likely to reflect differences in characteristics and support needs of people living in different settings rather than the effect of the residential setting itself.

A small proportion of adults (8.4%) were placed out-of-area at the time of their death. There was a statistically significant difference in the median age at death between groups, largely due to cases where out-of-area placement status was not known. However, when excluding cases where out-of-area status was not known, there was no significant difference in age at death between those placed out-of-area and those who were not (58.6 vs 57.2 years, respectively; see Appendix 1.8).

Contact with the criminal justice system in the five years before death was uncommon (0.7%); however, it was associated with a significantly lower median age at death than having no contact (43.1 vs 62.7 years, p<0.001). Mental health restrictions in the five years before death were recorded for 3.7% of adults with a learning disability. Although the median age at death differed significantly across mental health restriction categories when 'not known' responses were included (p<0.001) (Appendix 1.8), there was no statistically significant difference in median age at death between individuals with mental health restrictions in the five years before death and those without (p=0.856). Overall, many of the statistically significant group differences in these analyses were driven by 'not known' responses, highlighting the impact of missing or incomplete data on interpretation of findings.

Causes of death

Medical Certificate of Cause of Death (MCCD) data were available for 2,692 (99.2%) of the 2,713 completed reviews of adults with a learning disability who died in 2024 (Figure 1.7). The most common ICD-10 chapter (Appendix 1.9) causes of death among adults with a learning disability who died in 2024 and had a LeDeR review were: diseases of the respiratory system (16.6%), diseases of the circulatory system (16.2%), neoplasms (cancers) (15.5%), diseases of the nervous system (13.5%), and congenital malformations, deformations and chromosomal abnormalities (13.3%). A more detailed breakdown of ICD-10 chapter causes of death, and the most common underlying cause of death are provided in Appendices 1.10 and 1.11.

Overall, the distribution of causes of death in 2024 differed significantly from that of the general population ($p<0.001$). Deaths due to congenital malformations, deformations, and chromosomal abnormalities – including conditions such as Down syndrome, congenital heart defects, and other structural or genetic conditions – were markedly higher (13.3% vs 0.2%). Deaths from diseases of the respiratory system (16.6% vs 12.1%) and the nervous system (13.5% vs 7.9%) were also more common than in the general population. In contrast, deaths due to neoplasms (15.5% vs 27.1%) and diseases of the circulatory system (16.2% vs 23.9%) accounted for a smaller proportion of deaths than in the general population.

Between 2021 and 2024, the distribution of causes of death also changed significantly ($p<0.001$). Deaths due to respiratory diseases and neoplasms increased ($p<0.01$ and $p=0.034$, respectively), while other causes showed no significant changes. Congenital causes also increased slightly (from 11.4% to 13.3%), although this was not statistically significant. These trends should be interpreted in the context of 2021, when a high number of deaths were due to COVID-19. COVID-19 deaths are classified separately within the ICD-10 chapter on Provisional Assignment of New Diseases and are not included within the Diseases of the Respiratory System chapter. This may have reduced the relative proportion of other causes of death in 2021, with their contribution increasing as the impact of the pandemic declined. Interpretation should also consider possible inconsistencies in how underlying causes of death are recorded on the MCCD, particularly for adults with complex or multiple long-term conditions.

Figure 1.7: *Most common causes of death of adults with a learning disability (by ICD-10 chapter) compared with the general population*

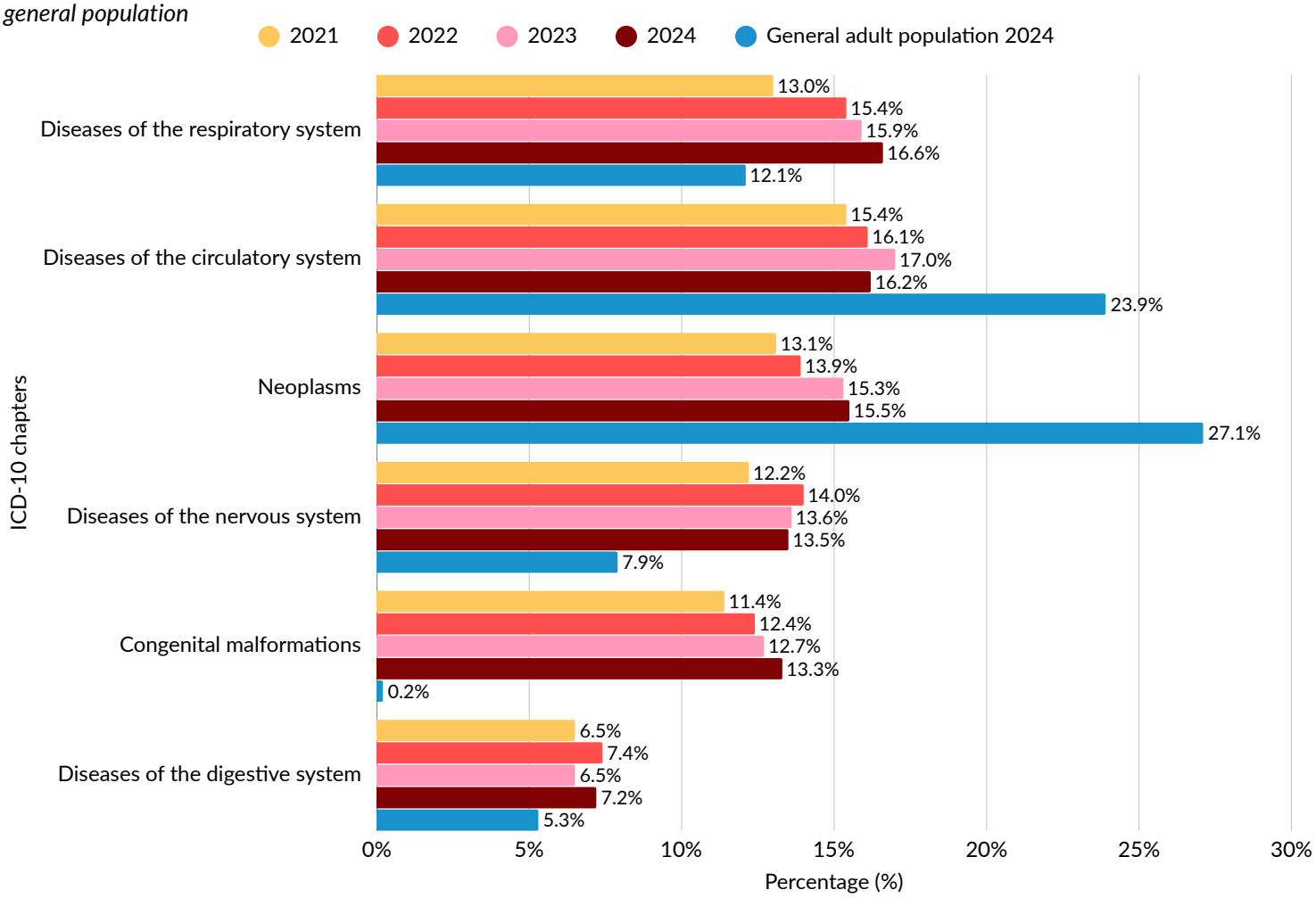


Table 1.4 shows the most common underlying causes of death in the MCCD data in LeDeR from 2021 to 2024. With the exception of COVID-19, the same four underlying causes are commonly reported over this time: Down syndrome and cerebral palsy, pneumonia, and epilepsy. Other commonly reported causes included respiratory conditions such as bronchopneumonia and unspecified lower respiratory tract infections, neurological conditions including dementia and stroke, and cardiovascular conditions such as acute myocardial infarction and atherosclerotic heart disease.

COVID-19 had a substantial but time-limited impact. It was the most commonly recorded underlying cause of death in 2021 and remained among the leading causes in 2022, although this ICD-10 category only includes deaths where COVID-19 infection was confirmed by laboratory findings. However, its prominence declined markedly in subsequent years, dropping to 10th place in 2023 and no longer appearing among the most common causes in 2024, reflecting the changing impact of the pandemic over time.

Overall, the pattern of mortality remained relatively stable across years, with respiratory, neurological, congenital, and cardiovascular conditions continuing to account for a substantial proportion of deaths among adults with a learning disability. The increasing prominence of pneumonia highlights the ongoing importance of prevention, early recognition, and management of respiratory illness in this population.

Table 1.4: *Most common underlying ICD-10 code causes of death of adults with a learning disability*

2021	2022	2023	2024
U07.1: COVID-19, virus identified 324 (11.9%)	Q90.9: Down syndrome, unspecified 284 (9.1%)	Q90.9: Down syndrome, unspecified 270 (8.9%)	Q90.9: Down syndrome, unspecified 269 (10.0%)
Q90.9: Down syndrome, unspecified 229 (8.4%)	G80.9: Cerebral palsy, unspecified 170 (5.4%)	J18.9: Pneumonia, unspecified 154 (5.1%)	J18.9: Pneumonia, unspecified 158 (5.9%)
G80.9: Cerebral palsy, unspecified 115 (4.2%)	U07.1: COVID-19, virus identified 156 (5.0%)	G80.9: Cerebral palsy, unspecified 152 (5.0%)	G80.9: Cerebral palsy, unspecified 108 (4.0%)
J18.9: Pneumonia, unspecified 98 (3.6%)	J18.9: Pneumonia, unspecified 137 (4.4%)	G40.9: Epilepsy, unspecified 92 (3.0%)	G40.9: Epilepsy, unspecified 89 (3.3%)
G40.9: Epilepsy, unspecified 74 (2.7%)	G40.9: Epilepsy, unspecified 99 (3.2%)	J18.0: Bronchopneumonia, unspecified 77 (2.5%)	F03: Unspecified dementia 66 (2.5%)
J18.0: Bronchopneumonia, unspecified 67 (2.5%)	J18.0: Bronchopneumonia, unspecified 76 (2.4%)	F03: Unspecified dementia 69 (2.3%)	I21.9: Acute myocardial infarction 57 (2.1%)
F03: Unspecified dementia 62 (2.3%)	F03: Unspecified dementia 64 (2.0%)	I21.9: Acute myocardial infarction 63 (2.1%)	J22: Unspecified acute lower respiratory infection 51 (1.9%)
I21.9: Acute myocardial infarction 50 (1.8%)	I25.1: Atherosclerotic heart disease 61 (1.9%)	J22: Unspecified acute lower respiratory infection 56 (1.8%)	J18.0: Bronchopneumonia, unspecified 47 (1.7%)
I25.1: Atherosclerotic heart disease 49 (1.8%)	I21.9: Acute myocardial infarction 57 (1.8%)	I25.9: Chronic ischaemic heart disease, unspecified 52 (1.7%)	I25.1: Atherosclerotic heart disease 47 (1.7%)
I64: Stroke, not specified as haemorrhage or infarction 46 (1.7%)	I25.9: Chronic ischaemic heart disease, unspecified 56 (1.8%)	U07.1: COVID-19, virus identified 50 (1.6%)	I64: Stroke, not specified as haemorrhage or infarction 45 (1.7%)

*Although Down syndrome and cerebral palsy should not be listed as the only cause of death or included in part 1A on the MCCD (Department of Health and Social Care, 2023), it may be appropriate for them to be listed as the underlying cause of death if the sequence of events or conditions that lead to death is fully recorded, and Down syndrome or cerebral palsy likely resulted in the condition (e.g., if the death was due to a congenital heart defect associated with Down syndrome) (see guidance for completing death certificates).
See Appendix 1.11 for a more detailed underlying ICD-10 code causes of death breakdown and Appendix 1.12 for the colour code of Table 1.4.

Avoidable Mortality

Table 1.5 shows that 1,049 (39.0%) of the 2,692 deaths in 2024 that had a known cause of death were classed as avoidable. The proportion of avoidable mortality was significantly higher than in the general population (39.0% vs 21.1%, $p<0.001$). However, the proportion of avoidable mortality of adults with a learning disability has fallen over time, from 46.3% in 2021 to 39.0% in 2024 (43.4% in 2022 and 41.4% in 2023, using the latest available data). Statistical modelling confirmed this trend ($p<0.001$), estimating that the proportion of avoidable mortality fell by around 2.4 percentage points each year between 2021 and 2024. Over the same period, the proportion of avoidable mortality in the general adult population also declined, from 23.5% in 2021 to 21.1% in 2024.

Although the proportion of avoidable mortality in adults with a learning disability appeared highest in the 65–74 age group and was slightly higher in males than females (similar to the general population), there were no statistically significant differences in the distribution of avoidable mortality across age groups ($p=0.52$) or between the sexes ($p=0.19$) during 2021–2024. When compared with the general population, however, avoidable mortality as a proportion of overall deaths in adults with a learning disability was significantly higher within each age group examined, and among both males and females (all $p<0.001$).

It is important to note that the overall percentages presented for the general population are influenced by the large proportion of deaths occurring in adults aged 75 years and over, which are not classified as avoidable under the OECD definition (OECD, 2022). When expressed as a proportion of all deaths with known causes within each population, avoidable deaths accounted for a higher share of mortality in adults with a learning disability than in the general population across every age group, with the disparity most pronounced in younger age group of adults with a learning disability. For a more detailed breakdown of avoidable mortality see Appendix 1.13.

Table 1.5: *Avoidable mortality of adults with a learning disability*

Avoidable mortality	2021	2022	2023	2024	2024 (% of all deaths with known causes)	General adult population 2024	General adult (% of all deaths with known causes)
Avoidable mortality							
Avoidable (preventable and/or treatable) (95% CI)	1,263 (46.3%) (44.4-48.2%)	1,362 (43.4%) (41.7-45.2%)	1,260 (41.4%) (39.6-43.1%)	1,049 (39.0%) (37.1-40.8%)	1,049 (39.0%) (37.1-40.8%)	111,614 (21.1%) (21.0-21.3%)	111,614 (21.1%) (21.0-21.3%)
Preventable (95% CI)	626.5 (23.0%) (21.4-24.6%)	578 (18.4%) (17.1-19.8%)	483 (15.9%) (14.6-17.2%)	376.5 (14.0%) (12.7-15.4%)	376.5 (14.0%) (12.7-15.4%)	71,426.5 (13.5%) (13.4-13.6%)	71,426.5 (13.5%) (13.4-13.6%)
Treatable (95% CI)	636.5 (23.3%) (21.8-25.0%)	784 (25.0%) (23.5-26.5%)	777 (25.5%) (24.0-27.1%)	672.5 (25.0%) (23.4-26.7%)	672.5 (25.0%) (23.4-26.7%)	40,187.5 (7.6%) (7.5-7.7%)	40,187.5 (7.6%) (7.5-7.7%)
Total with known causes of death	2,728 (100.0%)	3,138 (100.0%)	3,046 (100.0%)	2,692 (100.0%)	2,692 (100.0%)	527,747 (100.0%)	527,747 (100.0%)
Avoidable mortality by age group							
18-24 years*	41 (39.0%)	51 (38.6%)	32 (33.3%)	37 (39.4%)	37 (1.4%)	891 (72.1%)	891 (0.2%)
25-49 years	253 (53.2%)	291 (53.5%)	239 (47.7%)	204 (45.8%)	204 (7.6%)	15,956 (77.4%)	15,956 (3.0%)
50-64 years	550 (56.3%)	591 (51.7%)	552 (48.7%)	448 (47.8%)	448 (16.6%)	40,631 (71.7%)	40,631 (7.7%)
65-74 years	419 (61.9%)	429 (56.4%)	437 (58.7%)	360 (56.7%)	360 (13.4%)	54,136 (48.5%)	54,136 (10.3%)
Avoidable mortality by sex							
Female	541 (45.9%)	558 (40.4%)	485 (38.6%)	442 (38.5%)	442 (16.4%)	43,293 (16.7%)	43,293 (8.2%)
Male	712 (46.8%)	779 (45.7%)	744 (42.9%)	578 (39.2%)	578 (21.5%)	67,750 (25.2%)	67,750 (12.8%)

*20-24 years in the general adult population 2024.

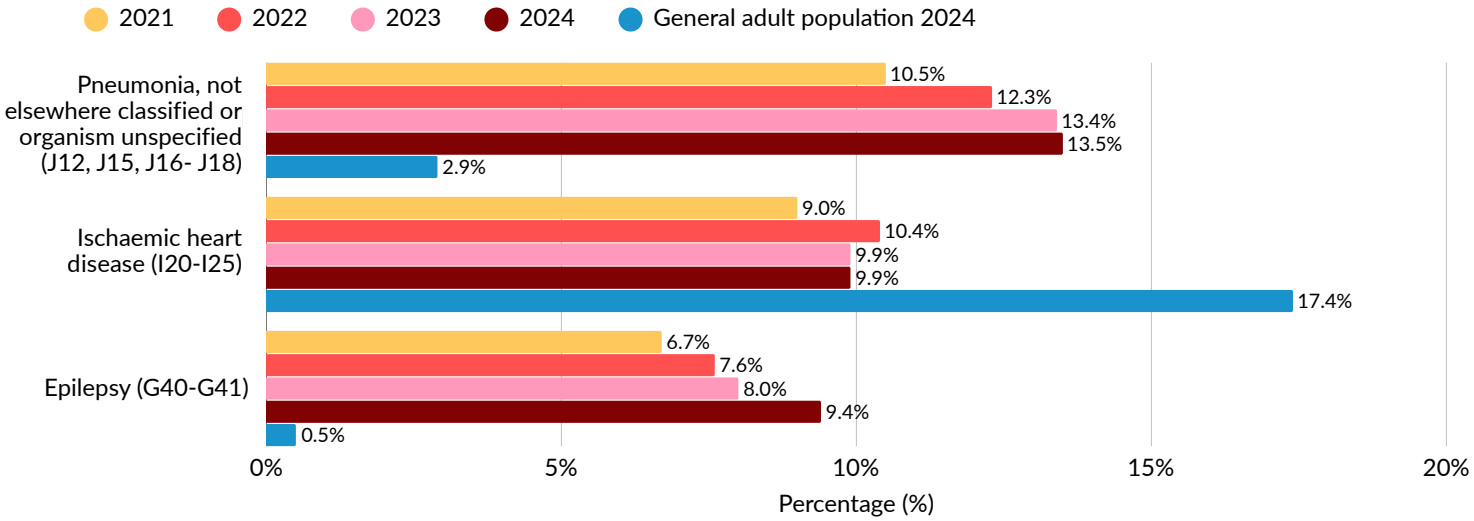
**Data presented as number (% of deaths with known causes in total, or within age or sex subgroup). The two additional showed the percentage % of all 2024 deaths with all known causes of deaths in that population (2024 denominator 2,692; general adult population 527,747).

In 2024, 14.0% of deaths were classified as preventable, significantly lower than in previous years, with 23.0% in 2021, 18.4% in 2022, and 15.9% in 2023. Statistical modelling confirmed a significant downward trend over this period ($p<0.001$), with the proportion of preventable mortality estimated to have fallen by around 2.9 percentage points each year. For context, 43.7% of deaths classified as preventable mortality in 2021 were due to COVID-19, and the initial reduction in preventable mortality may be accounted by lower rates of COVID-19 deaths.

In contrast, 25.0% of deaths in 2024 were classified as treatable, which is significantly higher than in the general population (7.6%; $p<0.001$). The proportion of treatable mortality remained broadly similar over time (23.3% in 2021, 25.0% in 2022, and 25.5% in 2023), and statistical modelling found no clear evidence of a change between 2021 and 2024 ($p=0.13$).

The most common causes of avoidable mortality among adults with a learning disability who died in 2024 were pneumonia (13.5% of avoidable mortality), ischaemic heart disease (9.9% of avoidable mortality), and epilepsy (9.4% of avoidable mortality). All three were significantly more common causes of avoidable mortality among adults with a learning disability than in the general population ($p<0.001$ each). Both pneumonia and epilepsy have increased over time as proportions of avoidable deaths. Figure 1.8 shows the breakdown and comparison to previous years and the general population.

Figure 1.8: *Most common causes of avoidable mortality (by OECD classification) of adults with a learning disability*

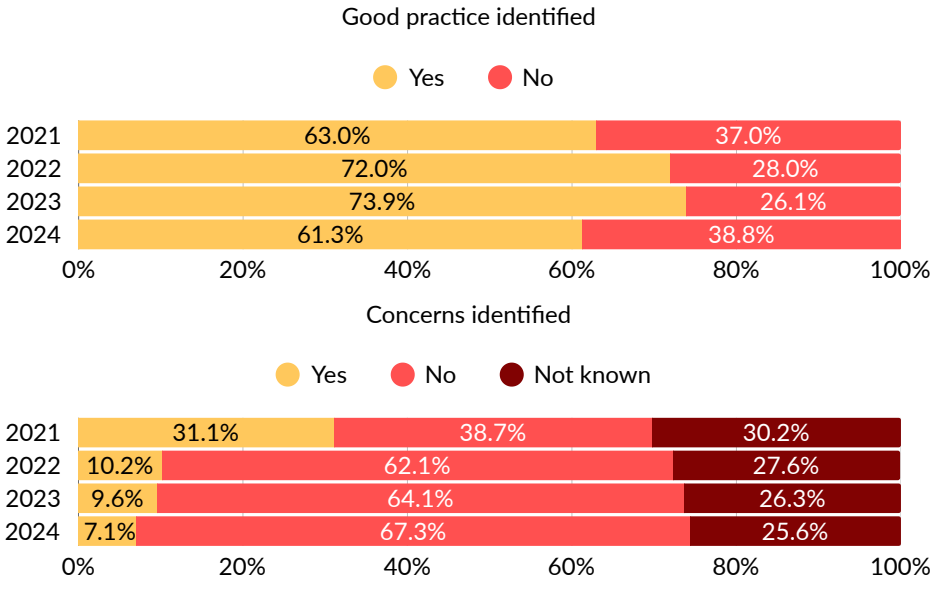


Appendix 1.14 presents avoidable causes of mortality by sex registered at birth, with comparisons to previous years and the general population. Differences by sex were minimal, although ischaemic heart disease was slightly more common in males. Pneumonia and epilepsy were significantly more common in adults with a learning disability than in the general population for both females and males.

Quality of Care

Figure 1.9 (continued overleaf) shows the different quality-of-care indicators from LeDeR reviews. For a more detailed breakdown, see Appendices 1.15–1.16.

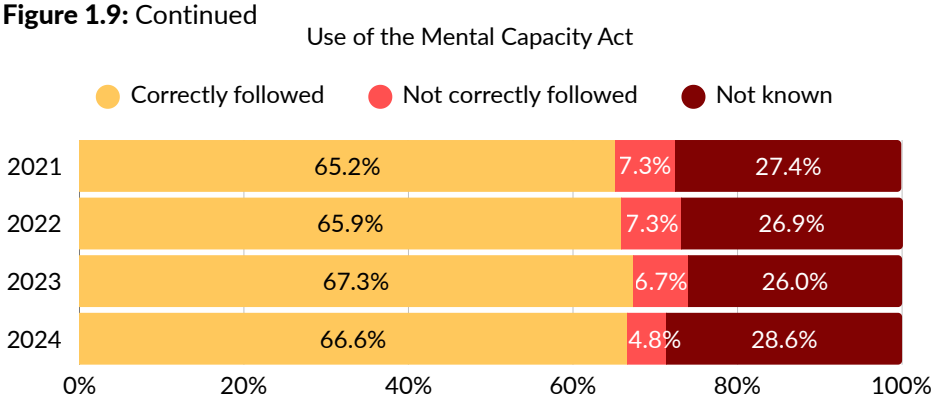
Figure 1.9: *Quality of care in adults with a learning disability by initial review*



Good practice was identified in the majority of initial reviews each year, although the proportion decreased in 2024 (61.3%) compared with 2023 (73.9%, $p<0.001$). This means that almost two in five initial reviews in 2024 did not record any examples of good practice.

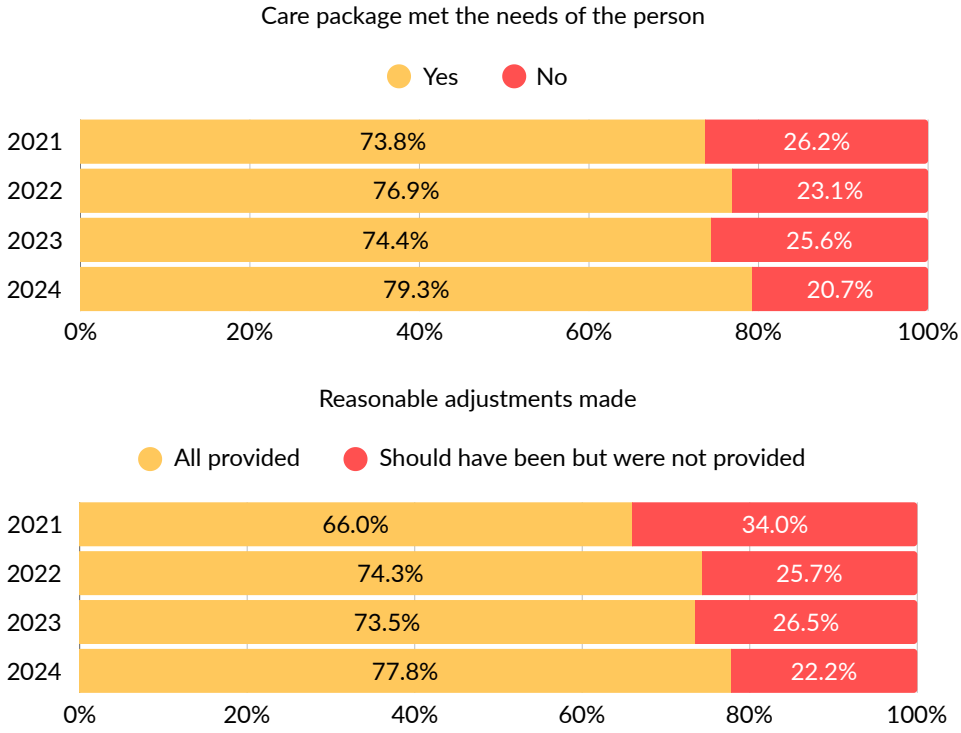
The proportion of initial reviews identifying concerns about care have changed significantly over time, decreasing from 31.1% in 2021 to 7.1% in 2024 ($p<0.001$).

Figure 1.9: Continued



The proportion of initial reviews that report that the Mental Capacity Act (MCA) was correctly followed differed significantly between 2021 and 2024, increasing from 65.2% to 66.6% (p<0.001).

Figure 1.10: *Quality of care in adults with a learning disability by focused review*



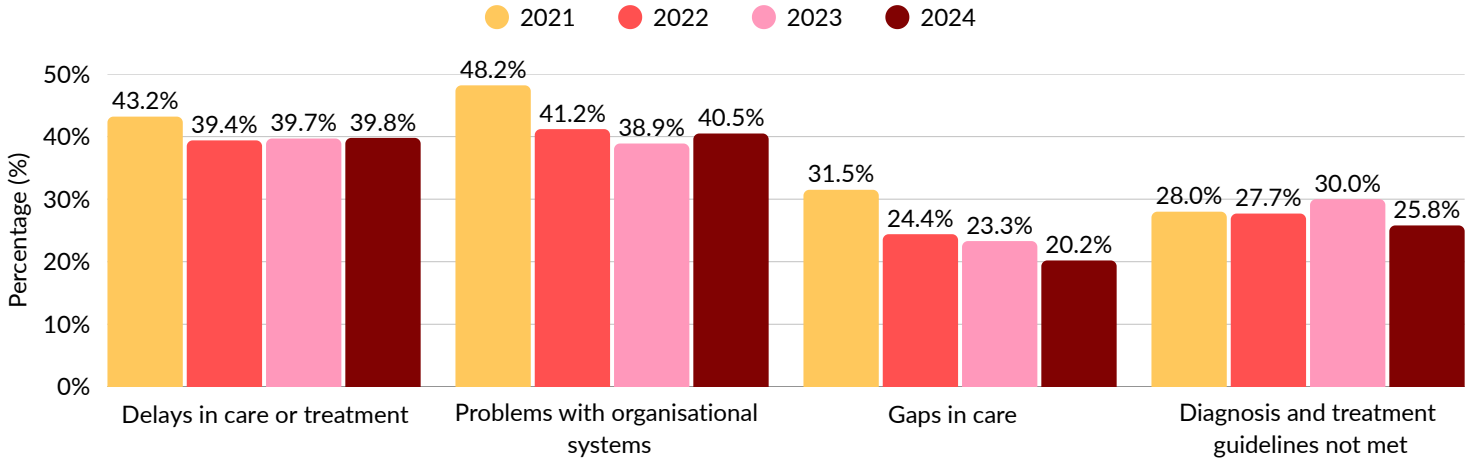
Most focused reviews reported that the care package met the needs of the person who died (79.3%), with no significant change in recent years (p=0.056). However, for one in five focused reviews (20.7%) reviewers felt the care package did not meet the person's needs, indicating gaps in adequate support.

The proportion of focused reviews indicating that all reasonable adjustments were provided differed significantly between 2021 and 2024, increasing from 66.0% to 77.8% (p<0.001), while 22.2% of adults were reported to have needed at least one reasonable adjustment that was not provided.

Reviews that identified specific problems in care

Reviewers reported whether adults with a learning disability experienced problems in their care, including delays, organisational or coordination issues, gaps in services, and failure to meet diagnostic or treatment guidelines. 39.8% of adults with a learning disability who died in 2024 experienced a delay in their care or treatment, slightly lower than in 2021 but similar to those who died in 2022 and 2023 (Figure 1.10). 40.5% experienced problems with organisational systems (an increase from 2023), and 20.2% experienced gaps in their care, while 25.8% received a diagnosis or treatment that did not meet guidelines (both decreases from previous years).

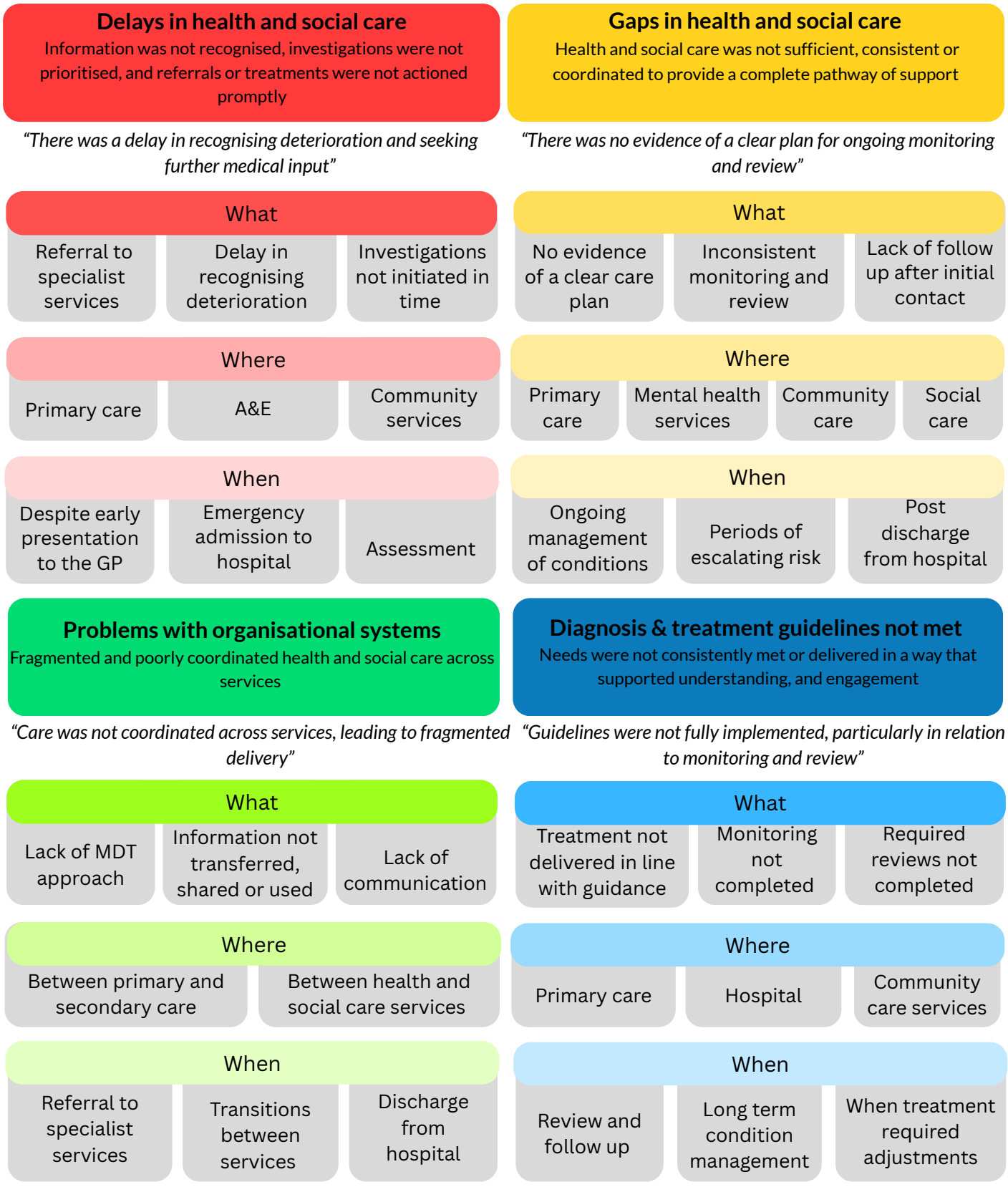
Figure 1.11: *Problems in care for adults with a learning disability*



Summary of problems with specific aspects of care

Adults with a learning disability experienced problems with care due to cumulative delays, gaps in provision and challenges across the health and social care system. Overall, the reported problems in care for adults with a learning disability were affected by systemic problems rather than isolated errors. Poor communication, incomplete documentation and lack of coordinated care planning between services were frequently noted by reviewers. These problems were intensified by service capacity pressures and inconsistent adherence to clinical guidelines, resulting in missed opportunities to deliver timely, appropriate, and person-centred health and social care. For full details on this analysis, please see the Research methods section.

Figure 1.12: *Qualitative framework analysis of problems with health and social care for adults with a learning disability*



Summary and discussion

Deaths continue to be well notified to LeDeR following a reduction in notifications in 2022, likely related to the COVID-19 pandemic, with sustained engagement evident in subsequent years. In 2024, just over four-fifths of notifications were submitted by health and social care professionals, representing a slight increase from the previous year and indicating continued engagement from health and social care partners with the reporting process.

Adults with a learning disability continue to die at a younger age than the general population, despite a gradual increase in the median age at death over time. In 2024, the median age at death for adults with a learning disability was 62.8 years, compared with 81.8 years in the general population. Over half of deaths occurred in individuals under the age of 65, a markedly different age distribution compared with the general population, where most deaths occur at ages 65 and above. Although the proportion of adults with a learning disability dying over the age of 65 is slowly increasing, it remains substantially lower than in the general population. Median age at death remained similar for males and females. While median age at death varied considerably among adults from ethnic groups other than “White”, it remained lower than that of adults from “White” ethnic backgrounds across 2021–2024.

The proportion of deaths classified as avoidable among adults with a learning disability who had a LeDeR review declined in 2024, continuing a downward trend observed since 2021. Despite this improvement, around two in five deaths of adults with a learning disability in 2024 were avoidable, nearly double the proportion seen in the general population. Avoidable mortality was driven primarily by treatable causes, which accounted for approximately a quarter of deaths, while preventable deaths represented a smaller, decreasing share compared with previous years.

In terms of causes of death, treatable respiratory system conditions (including pneumonia, bronchopneumonia and lower respiratory infections) increased as a proportion of causes of death between 2021 and 2024 and accounted for almost one in ten deaths. Furthermore, pneumonia remained the most common avoidable cause of death in 2024, accounting for almost one in seven avoidable deaths, a substantially higher proportion than in the general population, where it is one in 34 avoidable deaths. In a LeDeR deep dive report on pneumonia (White et al., 2024), we have shown that risk factors associated with these deaths were swallowing difficulties, impaired airway clearance, and postural problems. Care issues identified in those that died of pneumonia included lack of care staff training, skills or expertise for supporting people with a learning disability with complex health needs; delays in care (including delays in recognising and escalating signs of deterioration, diagnosis, referrals, and in admission or discharge from the hospital); and issues with health monitoring, risk assessment and documentation relating to known clinical risk factors for pneumonia.

Another pattern that has become apparent over recent years is the increase in long-term health conditions such as cardiovascular disease and neoplasms as common cause of death, similar to patterns in the general population. This is likely related to both lifestyle factors and the changing health profile of an ageing population of people with a learning disability. Ischaemic heart disease was the second most common cause of avoidable deaths in people with a learning disability, accounting for one in ten avoidable deaths. Although lower than in the general population, these causes of death may become more common in the future and thus should be an increasingly important focus for prevention.

Epilepsy remained a relatively common cause of death in 2024 and largely unchanged as proportion of overall deaths (around 3%) since 2021. It accounted for approximately one in eleven avoidable deaths, significantly higher than in the general population (where it is an avoidable cause in only one in 200 deaths), an increase as proportion of overall avoidable deaths since 2021. Evidence using LeDeR data of adults who were known to have had epilepsy suggests that excess epilepsy-related deaths are not explained by the condition alone but are associated with poor quality care and gaps in service provision (Shankar et al., 2026). Other neurological conditions such as dementia and stroke are also increasingly prominent causes of death in people with a learning disability, in keeping with an ageing population.

Overall, the quality of care received by people with a learning disability presents a mixed picture. Good practice was identified in just over three-fifths of reviews in 2024, a notable decrease from 2023, indicating that fewer deaths were associated with care considered to be good or high quality. This decline is particularly concerning given improvements over time in compliance with the Mental Capacity Act, suggesting that legal processes are being met but other aspects of care, particularly those related to treatable causes of death, are not consistently improving. This warrants further exploration.

Encouragingly, several indicators show improvement. The proportion of adults with a social care package that met their needs increased to around four in five, and the provision of reasonable adjustments remained stable, with just under four-fifths of reviews indicating that all required adjustments were made. Gaps in health and social care and failure to meet diagnosis and treatment guidelines also appeared to decrease from just under half in 2021 to two in five reviews in 2024. However, problems with organisational systems remain among the most commonly identified problems in care; communication, service coordination and delivery, and a lack of MDT approaches continue to affect timely and effective care delivery.

Finally, there remains evidence that some MCCDs may not consistently identify the underlying cause of death in line with ICD-10 coding principles, particularly where lifelong conditions such as Down syndrome are recorded as the underlying cause of death. This resulted in Down syndrome being recorded as the most common cause of death in 2024, which could obscure avoidable causes of death (demonstrated in Chapter 3 of this report). This suggests a need for improved understanding and training in death certification, including among clinicians completing MCCDs and medical examiners responsible for reviewing and accepting them.

Taken together, these findings indicate that despite an improvement in the proportion of avoidable deaths of people with a learning disability, health and care challenges persist particularly with regard to treatable conditions such as respiratory infections, and management of long-term conditions such as epilepsy, that require urgent and targeted action.

Looking Forward

Priorities for health and care services:

1. **Tackling avoidable deaths due to respiratory infections**

- At social care level:
  - As health support for people with a learning disability is often the responsibility of care staff who may not have healthcare backgrounds, they should receive training in recognising signs of respiratory infection and deterioration, particularly for individuals with swallowing, airway and postural issues. A standardised training programme could be developed and rolled out to support consistent delivery of this training.
  - Pathways for escalation and specialist advice need to be clear and accessible.
- At health care level:
  - An intensified focus on early identification of illness, timely intervention and ensuring pro-active and explicit guidance to caregivers.
  - Vaccination for the prevention of respiratory infections should be strengthened by consistent application of eligibility criteria in accordance with national guidance. This should include adherence to the Mental Capacity Act, with best interest decision making where appropriate.
  - Using the Learning Disability Annual Health Checks as an opportunity for proactive identification and support of people with a learning disability to identify those at risk and enable equitable access to vaccination.
  - Improve awareness of increased risk for poor outcomes associated with respiratory infection in individuals with a learning disability who present to secondary care, with responsive pathways to ensure rapid investigation, diagnosis and treatment, in line with findings from the LeDeR pneumonia deep dive highlighting delays and variation in hospital care and application of best practice guidelines.
- At the policy level:
  - The Joint Committee on Vaccination and Immunisation (JCVI) should investigate expanding access to vaccinations for respiratory infections in people with a learning disability. The Green book only includes individuals with a severe learning disability or Down syndrome as being eligible for influenza vaccination (Ramsay, 2020). However, the seasonal influenza vaccination programme includes individuals with a learning disability more broadly for influenza vaccination. Furthermore, young people and young adults with a learning disability do not qualify for either the respiratory syncytial virus (unless pregnant) or pneumococcal vaccinations (unless they have a clinical condition placing them at higher risk of getting seriously ill). These additional vaccinations, particularly pneumococcal vaccination, may help to reduce avoidable deaths and should be considered for the national vaccination programme, and the Green book could be updated to reflect current NHS approach to flu vaccination.
  - Consider a focus on increased risk for complications from pneumonia in people with a learning disability within the Sepsis Modern Service Framework.
  - A pandemic preparedness strategy should include a focus on vulnerable individuals, including those with a learning disability.
  - The continued monitoring of admissions and outcomes (including deaths) of adults with a learning disability with respiratory infections is essential to ensure robust, high-quality data that can drive service improvement and accountability. Consider development or adoption of a standardised audit or quality improvement tool to support consistent data collection, benchmarking, and review.

2. **Continue to ensure equitable access to prevention and management of long-term conditions in people with a learning disability**

- At social care level:
  - Ensure support for healthy lifestyles are included in care packages and evaluated as part of care reviews, and that care staff and family caregivers understand the importance of healthier lifestyles (diet, exercise, etc.) to prevent long-term conditions.

- At health care level:
  - Ensure annual health checks cover both risk factors for and assessment of long-term conditions and that Health Action Plans are clearly structured to include preventative actions, with accessible versions that people with a learning disability can understand.
  - Ensure equitable access to chronic disease pathways for people with a learning disability, drawing on e.g. diabetes care pathways adapted for people with a learning disability.
- At policy level:
  - Ongoing monitoring of the health conditions and associated mortality of people with a learning disability at national and regional level to identify changing needs associated with an ageing population.

3. **Reducing avoidable deaths due to epilepsy**

- At social care level:
  - As health support for people with a learning disability and epilepsy is often the responsibility of care staff who may not have healthcare backgrounds, they should be trained in recognising change in presentation, management of seizures and managing epilepsy-related risk. A standardised training programme could be developed and rolled out to support consistent delivery of this training.
- At health care level:
  - Identify high risk groups - those at risk for sudden unexpected death in epilepsy (SUDEP), older people with epilepsy, genetic conditions that predisposes to severe epilepsy, and those not having regular review.
  - In high-risk groups, ensure regular review and medication optimisation using a multidisciplinary approach which has been shown to reduce mortality (Sun et al., 2023).
  - Use evidence-based tools such as the SUDEP and Seizure Safety Checklist and the NHS Right Care toolkit to manage safety issues such as nocturnal monitoring.
  - Clinicians should ensure caregivers know what to monitor for and when to seek additional support from health services.

4. **Improve recording of the cause of death of people with a learning disability in the MCCD**

- At policy level:
  - Chief Medical Examiner / Chief Coroner should consider how recording of underlying causes of death in the Medical Certificate of Cause of Death (MCCD) can be improved, with updated guidance and/or consistent implementation and training for certifying doctors and medical examiners to improve the accuracy and completeness of mortality data and reduce misclassification of congenital and chromosomal conditions as cause of death.

For research

- Research is needed to better understand the causes of and factors associated with avoidable deaths due to respiratory infections, epilepsy and long-term conditions among adults with a learning disability, including the impact of service-level variation.
- Further investigation is warranted into how respiratory infections as a leading cause of death in this population can be reduced, including identifying common pathogens, prevention strategies, care pathways, and the uptake and effectiveness of vaccination programmes, and addressing vaccine hesitancy among people with a learning disability, their families, and caregivers.
- Research is needed to optimise epilepsy management in people with a learning disability, including the role of medication optimisation, balancing clinical effectiveness and side effects, and how epilepsy specialist nurses and clinical pharmacists can work across community settings to improve outcomes.
- Further research should examine how good practice is identified in conditions commonly associated with avoidable deaths, shared, and implemented across health and social care systems, including both formal and informal routes of dissemination, to support consistent improvement in care quality.
- Further work is needed to understand how caregivers, families, and support staff can positively influence health behaviours and build health literacy among people with a learning disability, and to identify the most accessible routes into the health service for both recognised and undifferentiated symptoms.
- Ongoing monitoring and research using LeDeR reviews and wider epidemiological approaches into the changing health profiles and needs of people with a learning disability as the population ageing progresses.

Chapter 2

Deaths of Adults with a Severe or Profound Learning Disability

Introduction

Learning disability is a broad condition involving significant limitations in intellectual functioning and adaptive behaviour, emerging during the developmental period (World Health Organization, 2022). Classification ranges from mild to profound and is based primarily on the level of support needed with daily living skills. Most people with a learning disability have a mild or moderate learning disability, while a smaller proportion have a severe or profound learning disability (Patel et al., 2020).

Information included in this chapter

The data sources and analytical approach for this chapter are outlined in the Research methods section. Analyses are based on review data of 8,084 adults with a learning disability who died between January 2021 and December 2024 and who had a LeDeR review completed between June 2021 and November 2025, and for whom a level of learning disability was recorded in their LeDeR review. Here we compare individuals with a mild to moderate learning disability and those with a severe to profound learning disability; further findings with a more detailed breakdown by levels of learning disability (mild; moderate; severe; profound) are presented in Appendices 2.1–2.5.

LeDeR review data by level of learning disability

Between 2021 and 2024, 8,084 out of 11,687 adults with a learning disability reported to LeDeR had a recorded level of learning disability in their initial or focused reviews. Of these, 64.7% were recorded as having a mild or moderate learning disability and 35.3% as having a severe or profound learning disability (Table 2.1). Although there was a statistically significant difference across years (p=0.010), proportions were broadly consistent over time, with 2021 showing a slightly higher proportion of individuals with a severe or profound learning disability compared to subsequent years.

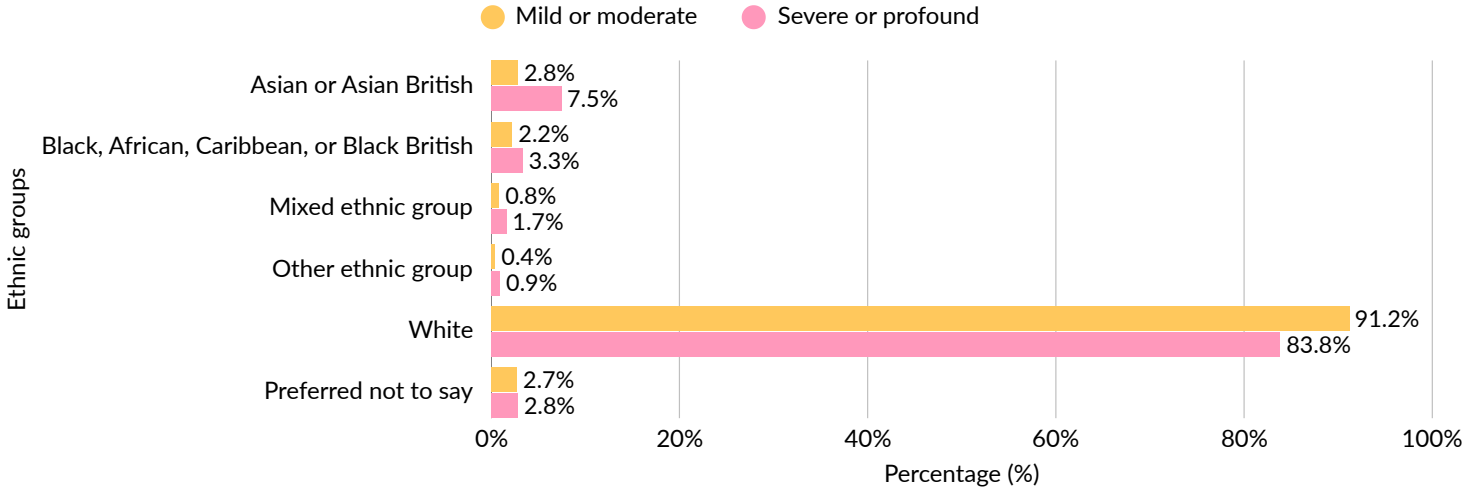
Table 2.1: *Annual deaths by level of learning disability*

Level of learning disability	2021	2022	2023	2024	Total
Mild or moderate	407 (60.0%)	1,252 (64.4%)	1,926 (66.6%)	1,646 (64.1%)	5,231 (64.7%)
Severe or profound	271 (40.0%)	691 (35.6%)	968 (33.4%)	923 (35.9%)	2,853 (35.3%)
Total	678 (100.0%)	1,943 (100.0%)	2,894 (100.0%)	2,569 (100.0%)	8,084 (100.0%)

Demographics by level of learning disability

Among adults with a recorded level of learning disability who died between 2021 and 2024, the distribution of sex registered at birth was similar across groups (Appendix 2.6). However, ethnic group distribution differed significantly (p<0.001). While the majority of adults in both groups were reported as “White”, a higher proportion of adults with severe or profound learning disability were from “Asian or Asian British”, “Black African, Caribbean, or Black British”, “Mixed”, and “Other” ethnic groups compared with adults with a mild or moderate learning disability (Figure 2.1).

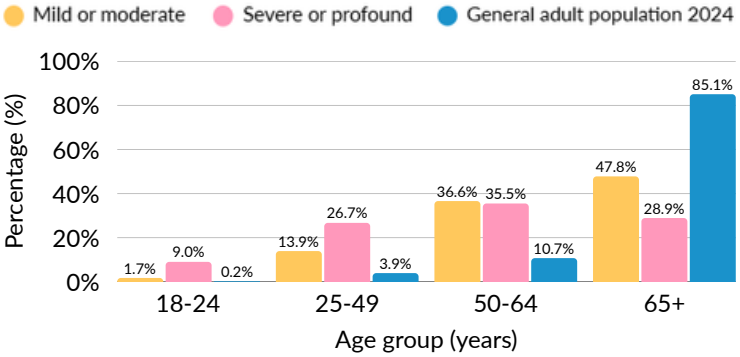
Figure 2.1: *Ethnicity by level of learning disability*



Age at death by level of learning disability

Over a third (35.7%) of adults with a severe or profound learning disability died before the age of 50, compared with 15.6% of adults with a mild or moderate learning disability (Figure 2.2). Consistent with this pattern, median age at death decreased with increasing severity of learning disability. Adults with a mild learning disability had a median age at death of 64.9 years, compared with 63.9 years for adults with a moderate learning disability, 59.0 years for adults with a severe learning disability, and 40.7 years for adults with a profound learning disability (Appendices 2.2–2.7). Adults with profound learning disability died more than 20 years younger on average than those with a mild learning disability, and approximately 40 years younger than those in the general population. This may partly reflect the higher prevalence of co-occurring physical health conditions among adults with a profound learning disability. See Appendix 2.8 for long-term conditions by level of learning disability.

Figure 2.2: *Age group at death by level of learning disability*



Circumstances of death by level of learning disability

This section compares the circumstances of death of adults with a mild or moderate and severe or profound learning disability. Table 2.2 shows that most deaths in both groups occurred in acute hospitals (55.6% and 56.9%), followed by the person's home (17.9% and 19.2%) and residential nursing homes (17.5% and 16.7%). The distribution of place of death differed significantly between adults with a mild or moderate and a severe or profound learning disability (p=0.026), and between adults with a severe or profound learning disability and the general population (p<0.001). Adults with a severe or profound learning disability were more likely to die in hospital (59.3% vs 42.0%) and less likely to die in a private home (19.6% vs 28.2%) or in hospices (2.2% vs 5.5%) than the general population.

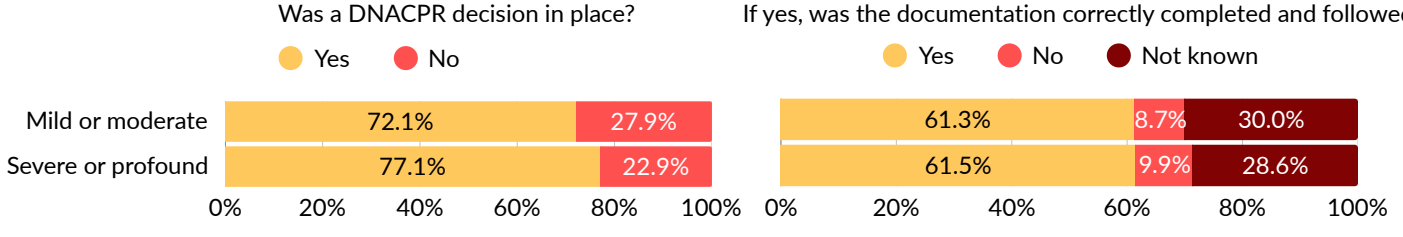
Table 2.2: *Place of death by level of learning disability*

Place of death	Mild or moderate	Severe or profound	General adult population 2024*
Acute hospital	2,910 (55.6%)	1,623 (56.9%)	221,050 (42.0%)
Assessment and treatment unit	8 (0.2%)	5 (0.2%)	
Community hospital	134 (2.6%)	63 (2.2%)	
Home of the person who died	935 (17.9%)	548 (19.2%)	148,517 (28.2%)
Home of a friend or relative	34 (0.6%)	11 (0.4%)	
Residential nursing home	915 (17.5%)	476 (16.7%)	114,524 (21.8%)
Hospice	137 (2.6%)	62 (2.2%)	29,067 (5.5%)
Others**	152 (2.9%)	55 (1.9%)	12,905 (2.5%)
Not known	6 (0.1%)	10 (0.4%)	0 (0.0%)
Total	5,231 (100.0%)	2,853 (100.0%)	526,063 (100.0%)

*ONS categories were grouped for comparability: hospitals (NHS and non-NHS), hospices (NHS and non-NHS), and care homes (local authority and non-local authority) were combined; private home includes own and friend or relative's homes; "elsewhere" and communal establishments were classified as "other", "prison", and "secure unit". **Others include Other, Prison, and Secure unit.

Figure 2.3 shows that in initial reviews, adults with a severe or profound learning disability were more likely to have a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision recorded at the time of death (77.1% vs 72.1%, p<0.001). However, there was no difference between groups in whether DNACPR documentation was correctly completed and followed (p=0.114).

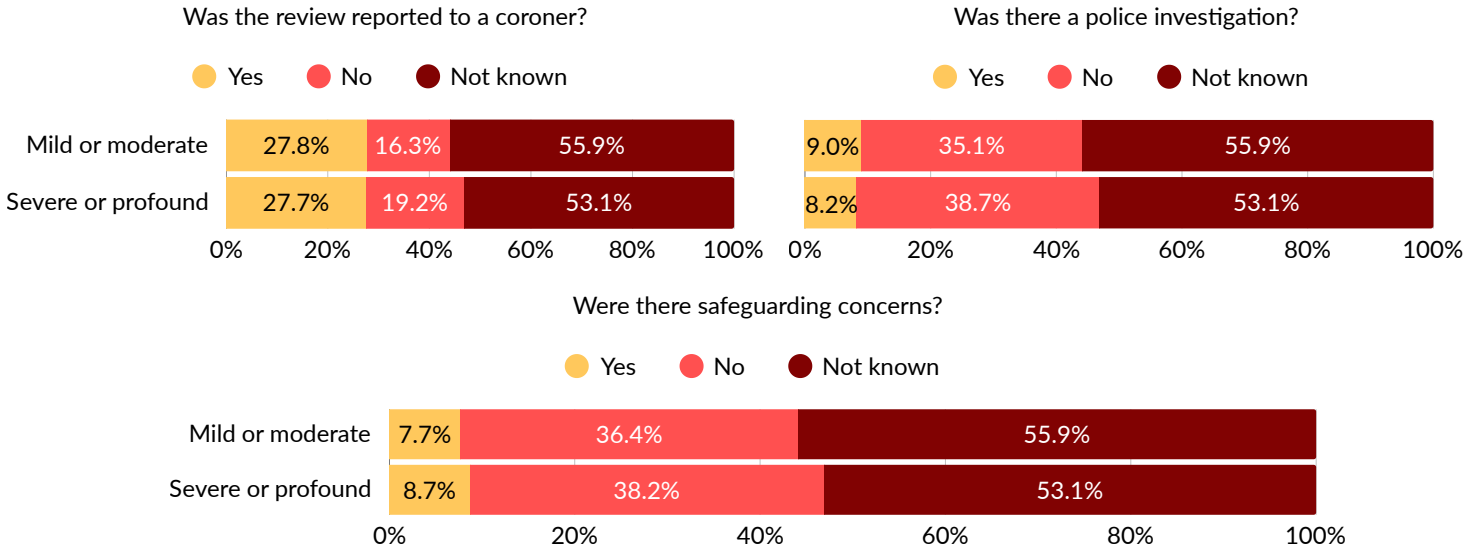
Figure 2.3: *DNACPR decision by level of learning disability*



Coroner referral rates were almost identical between groups (27.7% vs 27.8%), despite reaching statistical significance ($p<0.01$). Deaths of adults with a mild or moderate learning disability were slightly more likely to involve a police investigation (9.0% vs 8.2%; $p<0.01$).

Deaths of adults with a severe or profound learning disability were more likely to have a safeguarding concern raised than those with a mild or moderate learning disability (8.7% vs 7.7%, $p=0.040$) (Figure 2.4). In both groups, proportions were substantially higher than in the general adult population (1.4%; ONS, 2025), possibly reflecting greater support needs, care complexity, and identification of safeguarding risks. Further details are presented in Appendices 2.9–2.10.

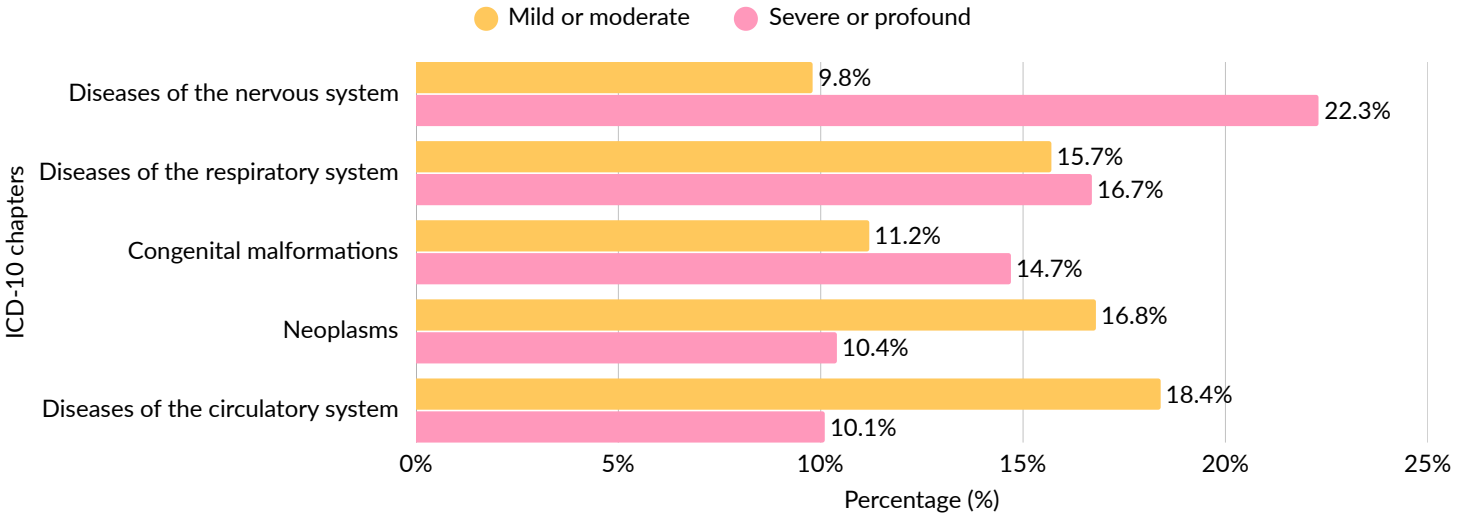
Figure 2.4: *Deaths reported to a coroner, police investigation, and safeguarding concerns by level of learning disability*



Causes of death by level of learning disability

Figure 2.5 presents the most common ICD-10 chapter underlying causes of death by level of learning disability. The overall distribution of causes of death differed significantly across groups ($p<0.001$). Diseases of the nervous system (including epilepsy) (22.3% vs 9.8%) and congenital malformations, deformations and chromosomal abnormalities (14.7% vs 11.2%) were significantly more common in adults with a severe or profound learning disability, while diseases of the circulatory system (18.4% vs 10.1%) and neoplasms (16.8% vs 10.4%) were more common in adults with a mild or moderate learning disability (all $p<0.001$). Diseases of the respiratory system had no significant difference between groups (16.7% vs 15.7%). When examined by detailed level of learning disability (Appendix 2.3), deaths due to diseases of the nervous system increased substantially with severity, accounting for over a third (36.2%) of deaths among adults with a profound learning disability compared with 8.0% among those with a mild learning disability. In contrast, deaths due to neoplasms and diseases of the circulatory system became progressively less common with increasing severity of learning disability. A more detailed breakdown of the most common ICD-10 chapter and underlying causes of death by level of learning disability is presented in Appendices 2.11–2.12.

Figure 2.5: *Most common causes of death (by ICD-10 chapter) by level of learning disability*



Avoidable mortality by level of learning disability

Adults with a mild or moderate learning disability were more likely to die from an avoidable cause of death than those with a severe or profound learning disability (43.3% vs 40.5%; *p*=0.016). Avoidable mortality was substantially higher in both groups than in the general population (21.1%; both *p*<0.001).

When examining types of avoidable mortality by level of learning disability, preventable mortality was more common among adults with a mild or moderate learning disability (18.5% vs 13.4%; *p*<0.001), while treatable mortality was more common among adults with a severe or profound learning disability (27.1% vs 24.7%; *p*=0.018). Treatable mortality in both groups was markedly higher than in the general population (7.6%; both *p*<0.001). A more detailed table of avoidable mortality by level of learning disability can be found in Appendix 2.13.

Table 2.3: *Avoidable mortality by level of learning disability*

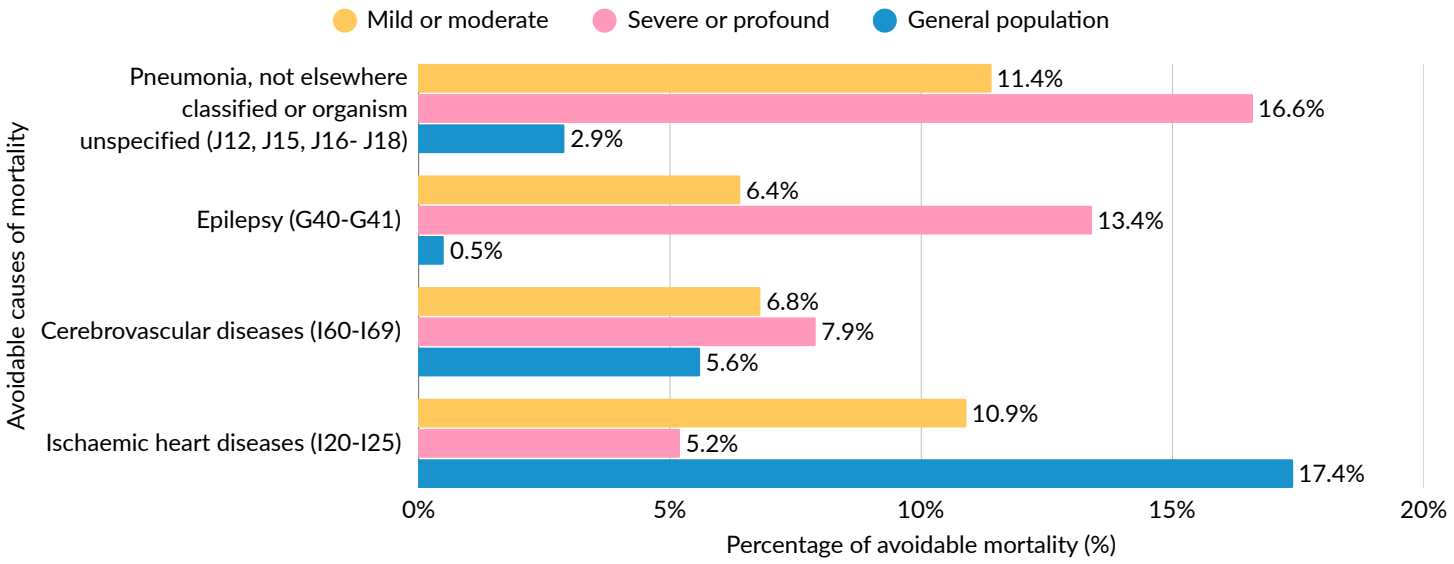
Avoidable mortality	Mild or moderate	Severe or profound	General adult population 2024
Avoidable (preventable and treatable) (95% CI)	2,246 (43.3%) (41.9–44.6%)	1,145 (40.5%) (38.7–42.3%)	111,614 (21.1%) (21.0–21.3%)
Preventable (95% CI)	962.5 (18.5%) (17.5–19.6%)	377.5 (13.4%) (12.1–14.6%)	71,426.5 (13.5%) (13.4–13.6%)
Treatable (95% CI)	1,283.5 (24.7%) (23.6–25.9%)	767.5 (27.1%) (25.5–28.8%)	40,187.5 (7.6%) (7.5–7.7%)
Total with known causes of death	5,189 (100.0%)	2,827 (100.0%)	527,747 (100.0%)

Causes of avoidable mortality by level of learning disability

As shown in Figure 2.6, the overall distribution of avoidable causes of mortality differed significantly across all three groups (*p*<0.001). The three most common avoidable causes of mortality in adults with a mild or moderate learning disability were treatable pneumonia (11.4%), treatable and preventable ischaemic heart diseases (10.9%), and treatable and preventable cerebrovascular diseases (6.8%). In adults with a severe or profound learning disability, the most common causes of avoidable deaths were treatable pneumonia (16.6%), treatable epilepsy (13.4%), and treatable and preventable cerebrovascular diseases (7.9%).

Pneumonia (16.6% vs 11.4%) and epilepsy (13.4% vs 6.4%) were significantly more common in the severe or profound group (both *p*<0.001), while ischaemic heart diseases were more common in the mild or moderate group (10.9% vs 5.2%, *p*<0.001). Cerebrovascular disease occurred at similar rates in both groups (6.8% vs 7.9%, *p*=0.226). For most avoidable causes, mortality rates were significantly higher in both learning disability groups than in the general population. A detailed breakdown of avoidable causes of mortality is presented in Appendix 2.14.

Figure 2.6: *Most common causes of avoidable mortality (by OECD classification) by level of learning disability*



Quality of care by level of learning disability

Figure 2.7 shows quality-of-care indicators from initial reviews (see Appendix 2.15 for full results). Good practice was identified significantly more often in adults with a severe or profound learning disability than with a mild or moderate learning disability (71.5% vs 68.0%; *p*=0.012). In contrast, concerns were identified in similar proportions across groups (11.5% mild or moderate; 11.1% severe or profound). Adults with a severe or profound learning disability were also more likely to have the Mental Capacity Act (MCA) correctly followed (74.2% vs 63.3%; *p*<0.001).

Figure 2.7: *Good practice, concerns identified and use of the MCA by level of learning disability*

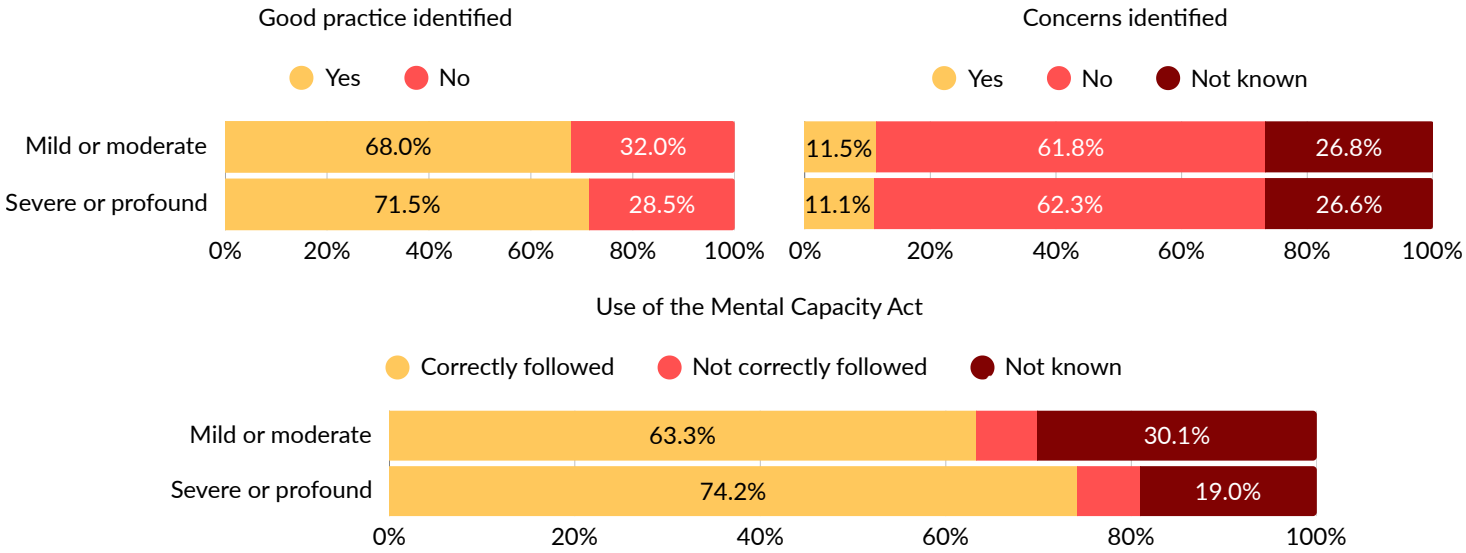
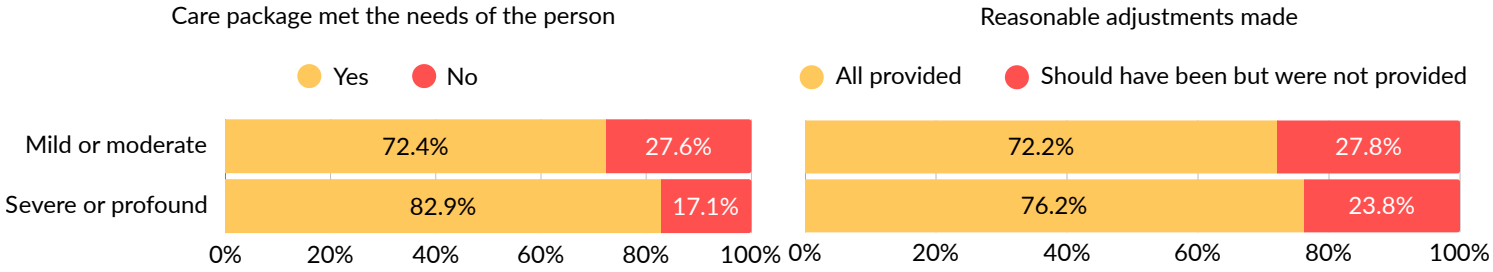


Figure 2.8 presents additional quality-of-care indicators from focused reviews (see Appendix 2.16 for full results), which were comparable to those in the 2023 report. Adults with a severe or profound learning disability were more likely than those with a mild or moderate learning disability to have a care package that met their needs (82.9% vs 72.4%; *p*<0.001) and to have reasonable adjustments in place (76.2% vs 72.2%; *p*=0.017).

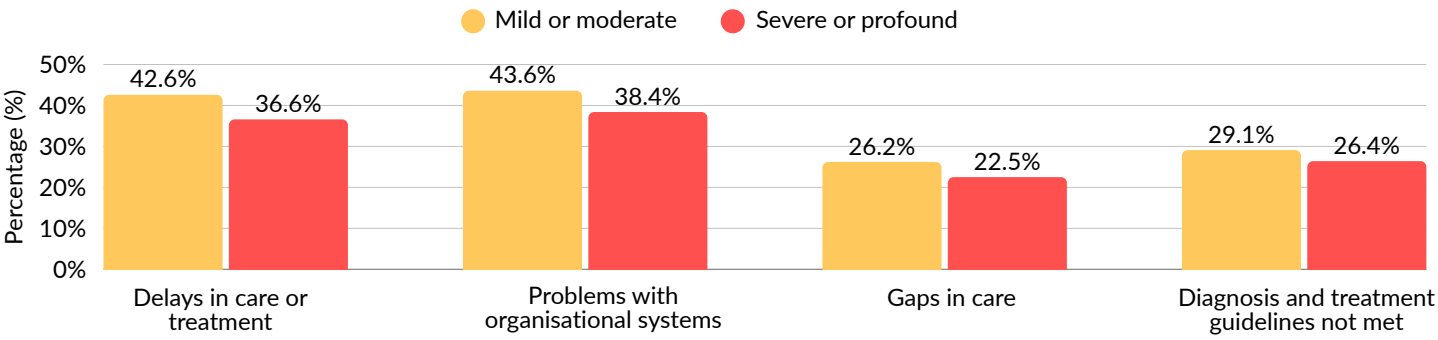
Figure 2.8: *Care packages and reasonable adjustments by level of learning disability*



Reviews that identified specific problems in care by level of learning disability

Reviewers reported problems in care for adults with a learning disability (Figure 2.9), most commonly problems with organisational systems (43.6% mild or moderate; 38.4% severe or profound) and delays in care or treatment (42.6% vs 36.6%). Gaps in care (26.2% vs 22.5%) and diagnosis or treatment guidelines not being met (29.1% vs 26.4%) were less frequent, and reported problems were slightly more common among adults with a mild or moderate learning disability. See Appendix 2.17 for more detailed information on specific problems in care by level of learning disability.

Figure 2.9: *Problems in care by level of learning disability*



Summary and Discussion

Adults with a severe or profound learning disability often have greater health and social care needs than those with a mild or moderate learning disability, including higher rates of multi-morbidity, congenital conditions, mobility limitations and communication difficulties (van Timmeren et al., 2017). They are more likely to require high levels of support and reasonable adjustments across care settings. Although they represent a smaller proportion of the overall learning disability population, their needs are substantial and distinct.

The findings in this chapter highlight clear differences in age at death and causes of death by level of learning disability. Adults with a severe or profound learning disability were more likely to die at a younger age, including before age 50, and were more likely to die from diseases of the nervous system and congenital or chromosomal conditions. In contrast, adults with a mild or moderate learning disability were more likely to die from circulatory diseases and neoplasms. These differences likely reflect underlying clinical complexity and life-course health risks (Emerson et al., 2011). Deaths associated with lifestyle-related conditions were more prominent among adults with mild or moderate learning disabilities, mirroring patterns seen in the general population.

Avoidable mortality remains markedly higher in both groups than in the general population. Adults with a severe or profound learning disability had a higher proportion of treatable causes of death. This may reflect challenges in recognising deterioration, communication barriers, diagnostic overshadowing, or delays in escalation of care (Heslop et al., 2014). It may also reflect differences in how clinical decision-making is approached in this group, including considerations around quality of life and appropriateness of escalation of care (Heslop et al., 2014). Pneumonia and epilepsy, both treatable causes of death, were the two most common causes of avoidable death in this group and often require early identification and proactive management. At the same time, while diseases of the nervous system accounted for more than a fifth of all deaths among adults with a severe or profound learning disability, only a small proportion of these — specifically epilepsy — are classified as avoidable. This distribution of underlying causes may partly explain the slightly lower overall proportion of avoidable deaths in people with a severe or profound learning disability despite high clinical complexity. In contrast, adults with a mild or moderate learning disability had a higher proportion of preventable deaths. This likely reflects a greater contribution of lifestyle-related and long-term conditions, such as cardiovascular diseases, which are more amenable to primary prevention. These patterns suggest missed opportunities for earlier intervention, including health promotion, risk factor management, and timely access to preventative healthcare highlight the importance of ensuring equitable access to public health interventions and preventative services for adults with a mild or moderate learning disability.

Quality-of-care indicators did not suggest systematic disadvantages for adults with a severe or profound learning disability compared with those with a mild or moderate learning disability. In several areas – including identification of good practice, social care packages meeting needs, and provision of reasonable adjustments – outcomes were similar or more favourable for adults with a severe or profound learning disability. However, these findings should be interpreted with caution, as they are based on reviewer assessments and may not reflect the views of families or caregivers. Indicators such as 'good practice' may reflect standard care rather than high-quality care, and the needs of people with more complex disabilities may not be fully recognised, potentially influencing how care quality is judged. Persistent reports of delays in care and organisational problems across both groups point to wider system pressures that affect all people with a learning disability.

Overall, while mortality patterns differ by level of learning disability, both groups experience substantially higher levels of avoidable — particularly treatable — mortality than the general population. Strengthening early recognition of deterioration, proactive management of conditions such as epilepsy and respiratory diseases, consistent delivery of reasonable adjustments, and coordinated cross-sector care remain critical to reducing inequalities in outcomes.

Looking Forward

Priorities for health and care services:

- A differentiated approach is needed to reduce avoidable deaths by level of learning disability. For adults with a severe or profound learning disability, the focus should be on treatable causes and ensuring equitable access to care and treatment, while for those with a mild or moderate learning disability, greater emphasis is needed on public health and preventable conditions in addition to tackling treatable causes of death.
- Given the high levels of multimorbidity, particularly among adults with a severe or profound learning disability, there should be a strong focus on multidisciplinary approaches and care coordination across services, supported by clear communication between primary care, acute services, and social care. Specialist learning disability professionals have an important role in supporting this.
- Persistent reports of delays in care and organisational issues across both groups highlight the need to strengthen escalation processes, ensuring timely access to specialist and clinical care, making use of health and care passports.
- For adults with a severe or profound learning disability, pneumonia and epilepsy should be key priorities, as leading causes of avoidable death. This includes proactive respiratory care (e.g. vaccination, early identification of deterioration, timely treatment) and strengthened epilepsy management in line with current guidance, including regular review, optimisation of treatment, and access to specialist epilepsy services (Royal College of Psychiatrists, 2017). See also suggestions in Chapter 1 to reduce avoidable deaths due to pneumonia and epilepsy.
- Support people with severe or profound learning disability to have investigations, through appropriate use of the Mental Capacity Act and offering desensitisation.

For research:

- Research is needed to understand how delays in recognising and responding to deterioration in adults with a learning disability can be reduced, and early detection and screening can be improved, particularly for those with a severe or profound learning disability.
- Further work should examine avoidable deaths from treatable causes, especially pneumonia and epilepsy, to identify where interventions can be most effective.
- Research should explore how best to manage multimorbidity in adults with a learning disability, including improving coordination of care across services.

Chapter 3

Deaths of Adults with Down syndrome

Introduction

Down syndrome, caused by the presence of an extra copy of chromosome 21, is the most common genetic cause of learning disability, affecting approximately one in 800 births worldwide (Antonarakis et al., 2020). It is associated with a distinct profile of physical characteristics, health conditions, and varying levels of cognitive impairment. People with Down syndrome often experience a higher prevalence of certain health needs, including congenital heart conditions, respiratory disorders, and an increased risk of early-onset Alzheimer's disease. However, as with all people with a learning disability, individuals with Down syndrome are a diverse group with differing abilities, life experiences, and support requirements.

Information included in this chapter

The data sources and analytical approach for this chapter are outlined in the Research methods section. Analyses are based on the review data of 1,986 adults with Down syndrome and 9,701 other adults with a learning disability who died between January 2021 and December 2024 and who had a LeDeR review completed by November 2025.

LeDeR review data of adults with Down syndrome and other adults with a learning disability

Of the 11,687 adults with a learning disability who died between 2021 and 2024 and received a LeDeR review by November 2025, 17.0% were recorded as having Down syndrome (Table 3.1). The proportion of adults who received a LeDeR review and had Down syndrome remained stable across this period, with no statistically significant change over time (p=0.577).

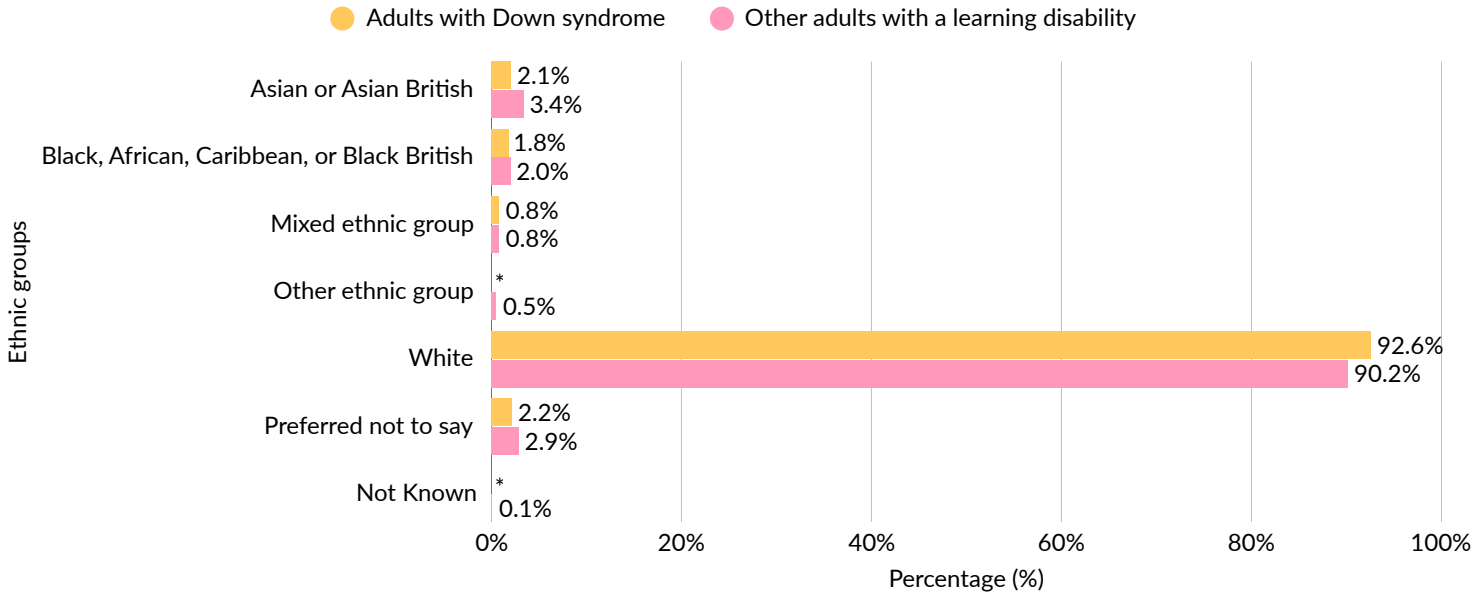
Table 3.1: *Annual deaths of adults with Down syndrome and other adults with a learning disability*

Down syndrome status	2021	2022	2023	2024	Total
Adults with Down syndrome	489 (17.8%)	538 (17.1%)	512 (16.7%)	447 (16.5%)	1,986 (17.0%)
Other adults with a learning disability	2,260 (82.2%)	2,616 (82.9%)	2,559 (83.3%)	2,266 (83.5%)	9,701 (83.0%)
Total	2,749 (100.0%)	3,154 (100.0%)	3,071 (100.0%)	2,713 (100.0%)	11,687 (100.0%)

Demographics of adults with Down syndrome and other adults with a learning disability

Among adults with a learning disability who died between 2021 and 2024, sex distribution was similar between adults with Down syndrome and other adults with a learning disability (Appendix 3.1). However, ethnic group distribution differed (p<0.01), showing that adults with Down syndrome were more likely to be recorded as "White" than other adults with a learning disability (92.6% vs 90.2%) (Figure 3.1).

Figure 3.1: *Ethnicity of adults with Down syndrome and other adults with a learning disability*



Age group at death of adults with Down syndrome and other adults with a learning disability

Figure 3.2: *Age group at death of adults with Down syndrome and other adults with a learning disability*

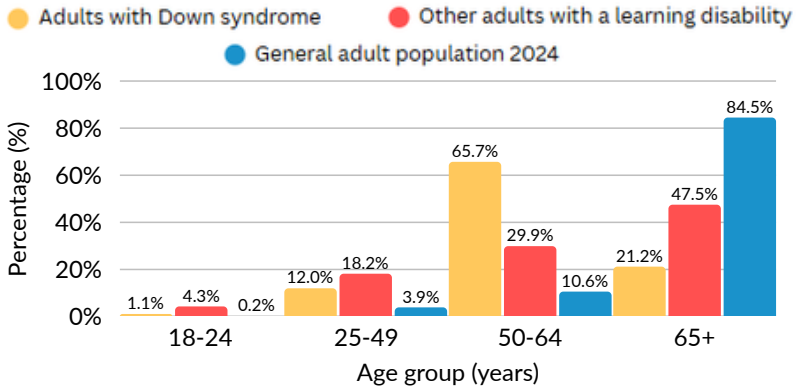


Figure 3.3: *Survival curve of adults with Down syndrome and other adults with a learning disability*

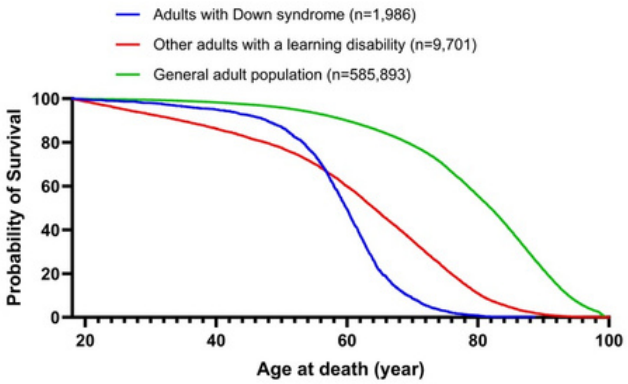


Figure 3.2 shows that over three-quarters (78.8%) of adults with Down syndrome died before the age of 65, compared with 52.4% of other adults with a learning disability.

Differences in age at death were accompanied by significant differences in long-term health conditions. Adults with Down syndrome had substantially higher rates of dementia than other adults with a learning disability (39.8% vs 5.1%; $p<0.001$). Higher proportions of visual impairment (36.5% vs 29.5%), hearing impairment (22.6% vs 14.5%), and thyroid disorders (12.1% vs 3.8%) were also identified through coded review data (all $p<0.001$). See Appendix 3.2 for a full breakdown of long-term conditions.

Figure 3.3 shows the survival curve comparing age at death across groups. The median age at death for adults with Down syndrome was 59.8 years (95% CI: 59.5–60.3 years), lower than other adults with a learning disability (64.1 years, 95% CI: 63.7–64.5 years) and the general adult population in England and Wales (2022) (81.9 years, 95% CI: 81.9–82.0 years) ($p<0.001$).

Circumstances of death of adults with Down syndrome and other adults with a learning disability

This section compares the circumstances of death of adults with Down syndrome and other adults with a learning disability. Most deaths in both groups occurred in acute hospitals (50.5% and 56.9%), followed by residential nursing homes (23.8% and 15.4%) and the person's home (19.5% and 19.6%) (Table 3.2). The distribution of place of death differed significantly between groups ($p<0.001$). The distribution of place of death also differed from the general population ($p<0.001$), with more deaths in hospital and care homes, and fewer in private homes and hospices.

Table 3.2: *Place of death of adults with Down syndrome and other adults with a learning disability*

Place of death	Adults with Down syndrome	Other adults with a learning disability	General adult population 2024**
Acute hospital	1,003 (50.5%)	5,521 (56.9%)	221,050 (42.0%)
Assessment and treatment unit	*	13 (0.1%)	
Community hospital	53 (2.7%)	217 (2.2%)	
Home of the person who died	387 (19.5%)	1,903 (19.6%)	148,517 (28.2%)
Home of a friend or relative	8 (0.4%)	56 (0.6%)	
Residential nursing home	472 (23.8%)	1,495 (15.4%)	114,524 (21.8%)
Hospice	33 (1.7%)	229 (2.4%)	29,067 (5.5%)
Others* **	26 (1.3%)	236 (2.4%)	12,905 (2.5%)
Not Known	*	31 (0.3%)	0 (0.0%)
Total	1,986 (100.0%)	9,701 (100.0%)	526,063 (100.0%)

*Fewer than five. **ONS place-of-death categories were regrouped to match those used in this report: NHS and non-NHS hospitals were combined into "hospital"; NHS and non-NHS hospices into "hospice"; and local-authority and non-local-authority care homes into "residential nursing home". "Private home" includes both the person's own home and that of a friend or relative. For the general population, "Others" comprises communal establishments and "elsewhere", that is, ONS categories other than those listed above. ***In LeDeR, "Others" comprises deaths recorded as Prison, Secure unit, or another place of death not listed above.

Adults with Down syndrome were more likely to have a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision (83.6% vs 71.7%, $p<0.001$), with no difference in correct completion or adherence (Figure 3.4).

Figure 3.4: *DNACPR decision of adults with Down syndrome and other adults with a learning disability*

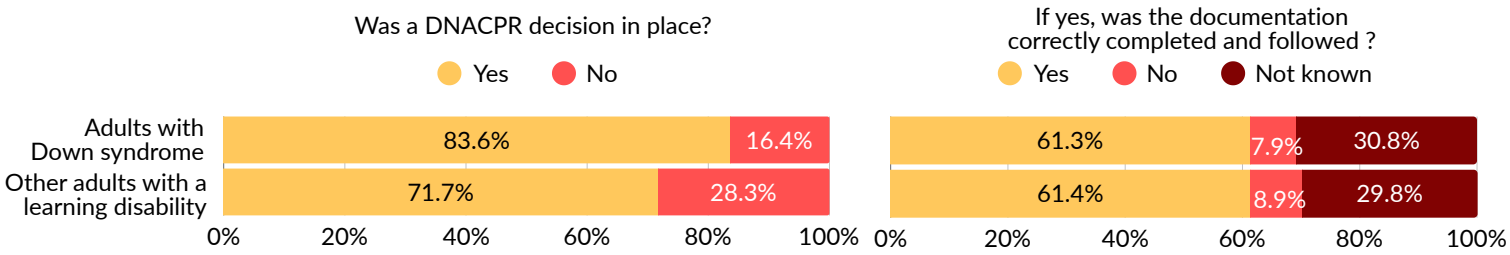
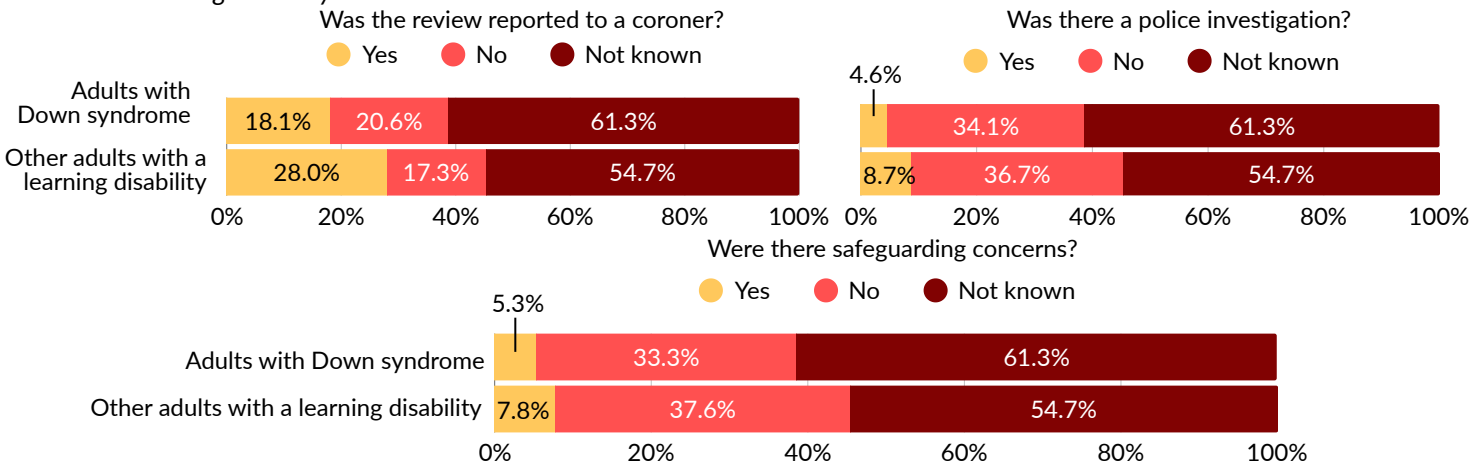


Figure 3.5 shows that, in initial reviews, deaths of adults with Down syndrome were less likely than those of other adults with a learning disability to be reported to a coroner (18.1% vs 28.0%, $p<0.001$), involve a police investigation (4.6% vs 8.7%, $p<0.001$), or have a safeguarding concern raised (5.3% vs 7.8%, $p<0.001$). However, the proportion with a safeguarding concern remained higher than in the general adult population (1.4%; ONS, 2025), suggesting ongoing safeguarding needs and service involvement. See Appendices 3.3–3.4 for a full breakdown.

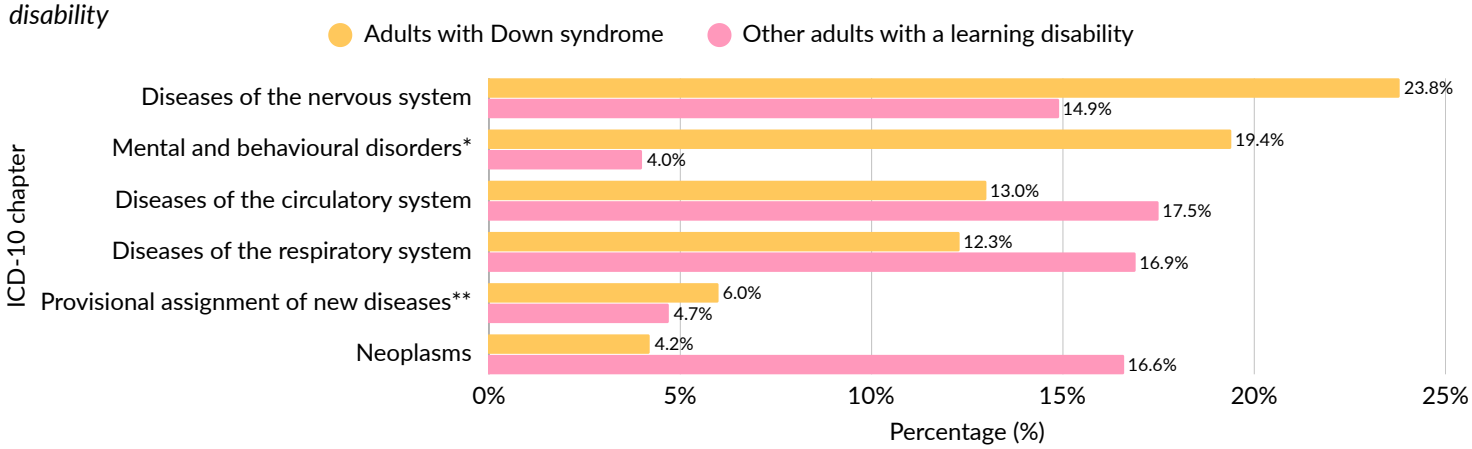
Figure 3.5: *Deaths reported to a coroner, police investigation, and safeguarding concerns of adults with Down syndrome and other adults with a learning disability*



Causes of death of adults with Down syndrome and other adults with a learning disability

Where Down syndrome was recorded as the underlying cause of death on the Medical Certificate of Cause of Death (MCCD), it was reassigned to the next listed condition to support more meaningful interpretation of causes of death in this group (see Appendix 0.3). Figure 3.6 shows that the distribution of underlying causes of death differed significantly between groups ($p<0.001$). Compared with other adults with a learning disability, adults with Down syndrome were more likely to die from diseases of the nervous system (including Alzheimer's disease) (23.8% vs 14.9%) and mental and behavioural disorders (including dementia) (19.4% vs 4.0%), and less likely to die from neoplasms (4.2% vs 16.6%) and diseases of the circulatory system (13.0% vs 17.5%) (all $p<0.001$). The most common underlying causes of death among adults with Down syndrome were unspecified dementia (17.3%) and early-onset Alzheimer's disease (10.0%) (Appendices 3.5-3.7).

Figure 3.6: *Most common causes of death (by ICD-10 chapter) of adults with Down syndrome and other adults with a learning disability*



*Mental and behavioural disorders (ICD-10 Chapter V) include deaths due to diagnosed medical conditions such as dementia, severe mental illness, or alcohol/substance-related disorders recorded on death certificates

**Provisional assignment of new diseases (ICD-10 Chapter XXII) includes deaths attributed to recently identified or emerging conditions that do not yet have a permanent ICD-10 classification (for example COVID-19 or newly recognised syndromes).

Avoidable mortality of adults with Down syndrome and other adults with a learning disability

Adults with Down syndrome died from avoidable causes at a comparable rate to other adults with a learning disability (47.0% vs 45.5%; p=0.230). Avoidable mortality was substantially higher in both groups than in the general population (21.1%; both p<0.001) (Table 3.3).

When examining forms of avoidable mortality among adults with a learning disability, preventable mortality was more common among other adults with a learning disability (18.8% vs 15.8%, p<0.01). While treatable mortality was the most common form of avoidable mortality in both adults with Down syndrome and other adults with a learning disability, it was significantly more common in adults with Down syndrome (31.2% vs 26.7%, p<0.001). Treatable mortality in both groups was markedly higher than preventable mortality, and higher than in the general population (7.6%; both p<0.001).

Table 3.3: *Avoidable mortality of adults with Down syndrome and other adults with a learning disability*

Avoidable mortality	Adults with Down syndrome	Other adults with a learning disability	General adult population 2024
Avoidable (preventable and treatable) (95% CI)	929 (47.0%) (44.8–49.2%)	4,381 (45.5%) (44.5–46.5%)	111,614 (21.1%) (21.0–21.3%)
Preventable (95% CI)	312 (15.8%) (14.2–17.5%)	1,809.5 (18.8%) (18.0–19.6%)	71,426.5 (13.5%) (13.4–13.6%)
Treatable (95% CI)	617 (31.2%) (29.2–33.3%)	2,571.5 (26.7%) (25.8–27.6%)	40,187.5 (7.6%) (7.5–7.7%)
Total with known causes of death	1,977 (100.0%)	9,626 (100.0%)	527,747 (100.0%)

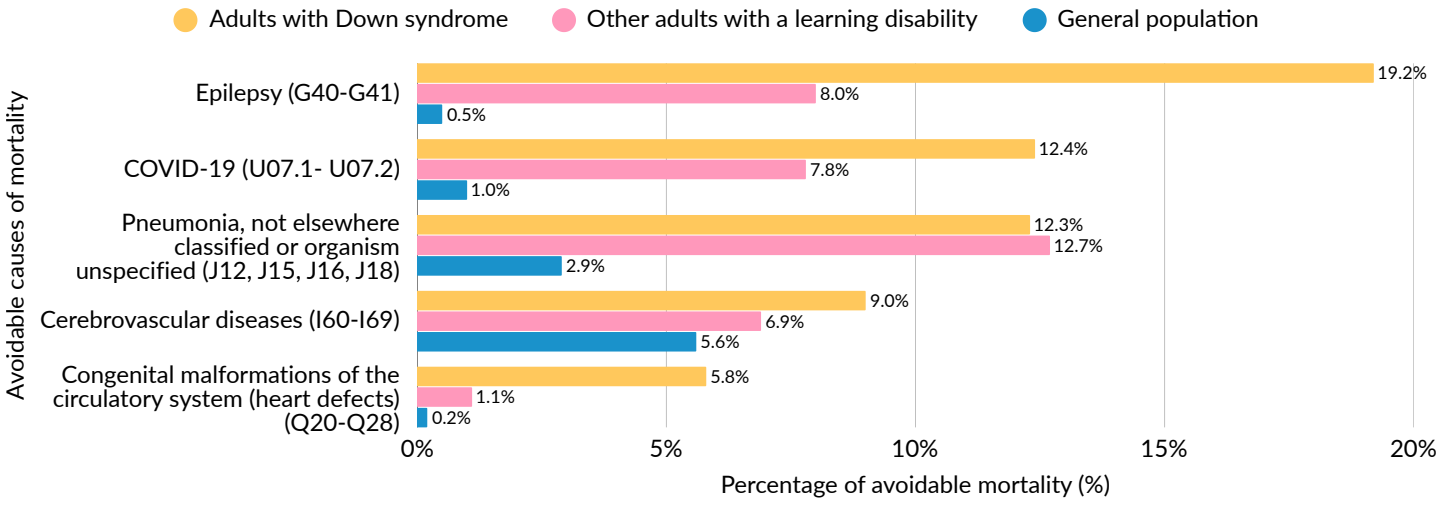
See Appendices 3.8–3.9 for more detailed tables of avoidable mortality by level of Down syndrome.

Causes of avoidable mortality of adults with Down syndrome and other adults with a learning disability

As shown in Figure 3.7, the overall distribution of avoidable causes of mortality differed significantly across all three groups (p<0.001). Treatable epilepsy (19.2% vs 8.0%), preventable COVID-19 (12.4% vs 7.8%), and treatable congenital malformations of the circulatory system (5.8% vs 1.1%) were more common in adults with Down syndrome. Preventable and treatable pneumonia was comparable between the two groups (12.3% vs 12.7%).

Both groups had substantially higher rates of treatable epilepsy and preventable and treatable pneumonia compared with the general population (0.5% and 2.9%, respectively). Further analyses in Appendices 3.10 and 3.11 identified additional differences between the groups. Treatable ischaemic heart diseases (4.4% vs 10.3%) and preventable accidental injuries (2.7% vs 4.0%) were more common in other adults with a learning disability. Adults with Down syndrome also consistently had higher proportions of avoidable deaths due to COVID-19 compared with other adults with a learning disability and the general population across all years, particularly in 2021 and 2022, at the height of the pandemic (see Appendix 3.12 for more detail).

Figure 3.7: *Most common causes of avoidable mortality (by OECD classification) of adults with Down syndrome and other adults with a learning disability*



Quality of care of adults with Down syndrome and other adults with a learning disability

Figure 3.8 shows selected quality-of-care indicators from initial reviews (see Appendix 3.13 for more detail). Good practice was identified at similar rates between adults with Down syndrome and other adults with a learning disability (67.0% vs 66.3%; p=0.561), while concerns were less common in adults with Down syndrome (12.6% vs 14.5%, p<0.001). The Mental Capacity Act (MCA) was more likely to be correctly followed for adults with Down syndrome (73.2% vs 64.9%, p<0.001).

Figure 3.8: Good practice, concerns identified, and use of the MCA *of adults with Down syndrome and other adults with a learning disability*

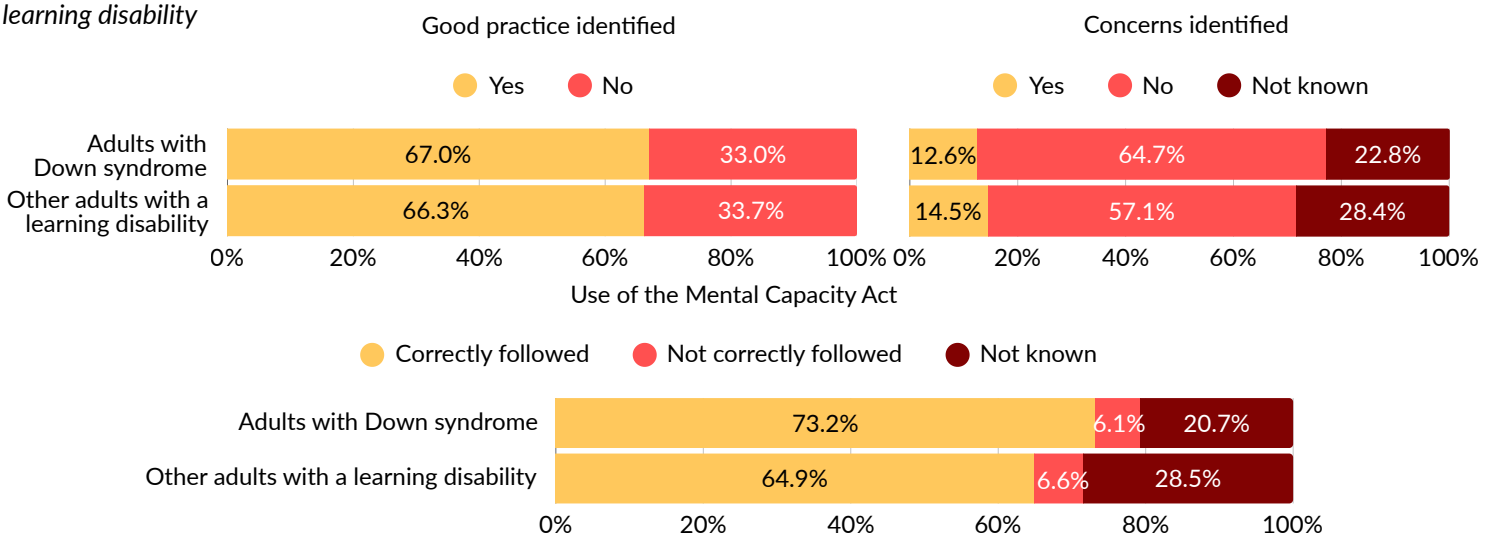
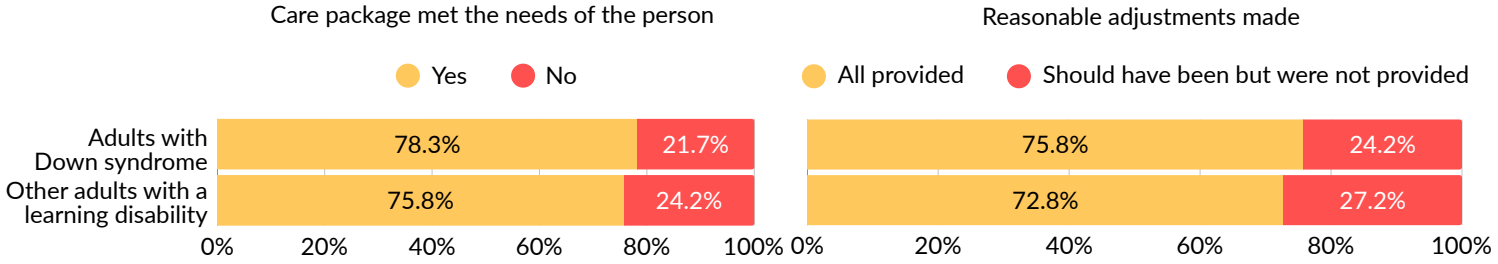


Figure 3.9 presents additional indicators from focused reviews (see Appendix 3.14 for more detail), showing similar rates of care packages reported by reviewers as meeting needs (78.3% vs 75.8%) and provision of reasonable adjustments needed (75.8% vs 72.8%) between groups (both p>0.05).

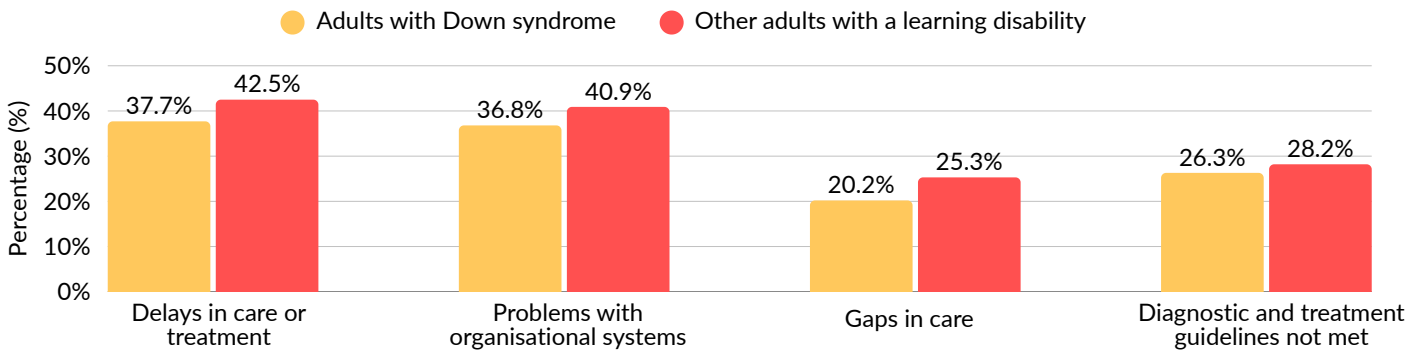
Figure 3.9: *Care packages and reasonable adjustments of adults with Down syndrome and other adults with a learning disability*



Reviews that identified specific problems in care of adults with Down syndrome and other adults with a learning disability

The most common problems with care reported by reviewers in both groups were delays in care or treatment (37.7% adults with Down syndrome, 42.5% other adults with a learning disability) and problems with organisational systems (36.8% vs 40.9%) (Figure 3.10). Across all categories, problems were reported less commonly in adults with Down syndrome than in other adults with a learning disability. See Appendix 3.15 for more details on specific problems in care for adults with Down syndrome.

Figure 3.10: *Problems in care of adults with Down syndrome and other adults with a learning disability*



Summary and discussion

Adults with Down syndrome have a distinct profile of health needs associated with trisomy 21 (Antonarakis et al., 2020). Adults with Down syndrome represent 17% of the learning disability population reviewed by LeDeR, consistent with wider evidence that Down syndrome is the most common identifiable cause of learning disability, representing approximately 15–20% of this population.

The findings in this chapter highlight clear differences in age at death and causes of death of adults with Down syndrome and other adults with a learning disability after accounting for adjustments where Down syndrome was recorded as the underlying cause of death in the MCCD. Adults with Down syndrome died at a younger median age compared to other adults with a learning disability. They were more likely to die from diseases of the nervous system and mental and behavioural disorders, driven largely by early-onset Alzheimer's disease. In contrast, other adults with a learning disability were more likely to die from diseases of the circulatory system and neoplasms. These patterns should be interpreted in the context of earlier mortality among adults with Down syndrome, as analyses are not age-standardised and therefore reflect both differences in underlying risk and age distribution. Nonetheless, the findings highlight the need for Down syndrome-specific care pathways, particularly for dementia services and epilepsy.

Avoidable mortality was comparable between adults with Down syndrome and other adults with a learning disability but remained substantially higher than in the general population. Treatable causes accounted for the largest proportion of avoidable deaths in both groups; however, adults with Down syndrome had a significantly higher proportion of treatable deaths, with epilepsy and pneumonia as the leading treatable causes of death. The high burden of treatable mortality may reflect both the unique health profile associated with Down syndrome, such as the development of seizures in Alzheimer's disease (Corniello et al., 2023), and challenges in recognising deterioration, communication barriers, diagnostic overshadowing, and delays in escalation of care. In contrast, other adults with a learning disability had a higher proportion of preventable deaths, reflecting a greater contribution of lifestyle-related and long-term conditions more amenable to primary prevention, such as ischaemic heart disease. However, preventable deaths due to COVID-19 were also a leading avoidable cause in adults with Down syndrome, reflecting heightened susceptibility to severe infection due to immune dysregulation and respiratory vulnerability associated with trisomy 21, including increased risk for pneumonia and influenza (Baksh et al., 2022; Illouz et al., 2021). This highlights the importance of recognising adults with Down syndrome as a priority group for vaccination and infection-prevention planning in future pandemics.

Quality of care indicators were broadly more favourable for adults with Down syndrome than for other adults with a learning disability. Adults with Down syndrome were more likely to have the Mental Capacity Act correctly followed and were less likely to have concerns identified in their care. Problems in care were also reported less commonly across all four categories, including delays in care or treatment, problems with organisational systems, diagnosis and treatment guidelines not met, and gaps in care, though these differences were modest.

Overall, adults with Down syndrome experience a distinct pattern of mortality and elevated burden of avoidable mortality compared with the general population, driven particularly by treatable causes including epilepsy and pneumonia, and preventable causes including COVID-19, and cerebrovascular diseases. Reducing these deaths will require strengthening early recognition of deterioration and proactive epilepsy management aligned with current specialist guidance. Given their heightened susceptibility to severe infection, targeted infection-prevention strategies, including prioritisation for relevant vaccinations, are also essential for adults with Down syndrome.

Looking forward

For health and care services:

- At the healthcare level:
  - Adults with Down syndrome should be recognised as having a distinct health profile across health and care services, particularly in primary care and acute settings. Services should review and adapt care pathways in line with the Down Syndrome Act 2022 (UK Parliament, 2022) and forthcoming statutory guidance to ensure provision reflects their specific health risks and needs. Development of specialist pathways and services may be required to meet health needs of groups of people with distinct health profiles and associated risks such as people with Down syndrome.
  - Proactive respiratory care should be prioritised for adults with Down syndrome to lower the risk of pneumonia and respiratory infections. This includes timely identification of respiratory deterioration, prompt treatment, and ensuring uptake of pneumococcal and influenza vaccination, alongside regular review of swallowing and aspiration risk.
  - Given the high burden of early-onset Alzheimer's disease, services should offer baseline assessment, and regular screening together with diagnostic pathways for adults with Down syndrome, ensuring input from specialist multi-disciplinary learning disability services in keeping with guidance (British Psychological Society, 2025).
- At the policy level:
  - Adults with Down syndrome, as well as people with a learning disability, should be considered a priority group in pandemic preparedness and infection-prevention planning, including prioritisation for vaccination and early protective measures, reflecting their increased vulnerability to severe infection (UK Covid-19 Inquiry, 2025); along with consideration of vaccination priority for respiratory infections including pneumonia.
  - The Chief Medical Examiner/ Chief Coroner and medical examiners should consider how to improve MCCD completion to ensure accurate recording of the underlying causes of death in those with Down syndrome (see also chapter 1).

For research:

- Research should build on LeDeR findings by linking to wider health and social care datasets and examining care pathways in more detail, to better identify the sociodemographic and clinical factors associated with avoidable causes of death in adults with Down syndrome and inform targeted interventions.
- Further work should examine where clinical interventions and care pathway improvements can be most effective in reducing the high burden of treatable causes of death (including from epilepsy and pneumonia) in adults with Down syndrome.
- Further work is needed to understand how care and treatment across health, social care, and specialist learning disability services can be strengthened to better meet the needs associated with early-onset dementia due to Alzheimer's disease in adults with Down syndrome, and for interventions to reduce the burden of disease and improve quality of life in older adults with Down syndrome.
- Adults with Down syndrome should be considered a priority group for trials of new medication treatments for Alzheimer's disease, as well as other interventions targeting dementia prevention and management.

Chapter 4

Review of the Lives and Deaths of Autistic Adults without a Learning Disability

Introduction

Autism is a lifelong neurodevelopmental condition characterised by differences in social communication, social interaction, sensory processing, and patterns of behaviour (World Health Organization, 2023). Autistic adults form a diverse population with varied cognitive profiles, life experiences, and support needs. While some autistic adults also have a learning disability, many do not. This chapter focuses on autistic adults without a learning disability whose deaths were reported to LeDeR.

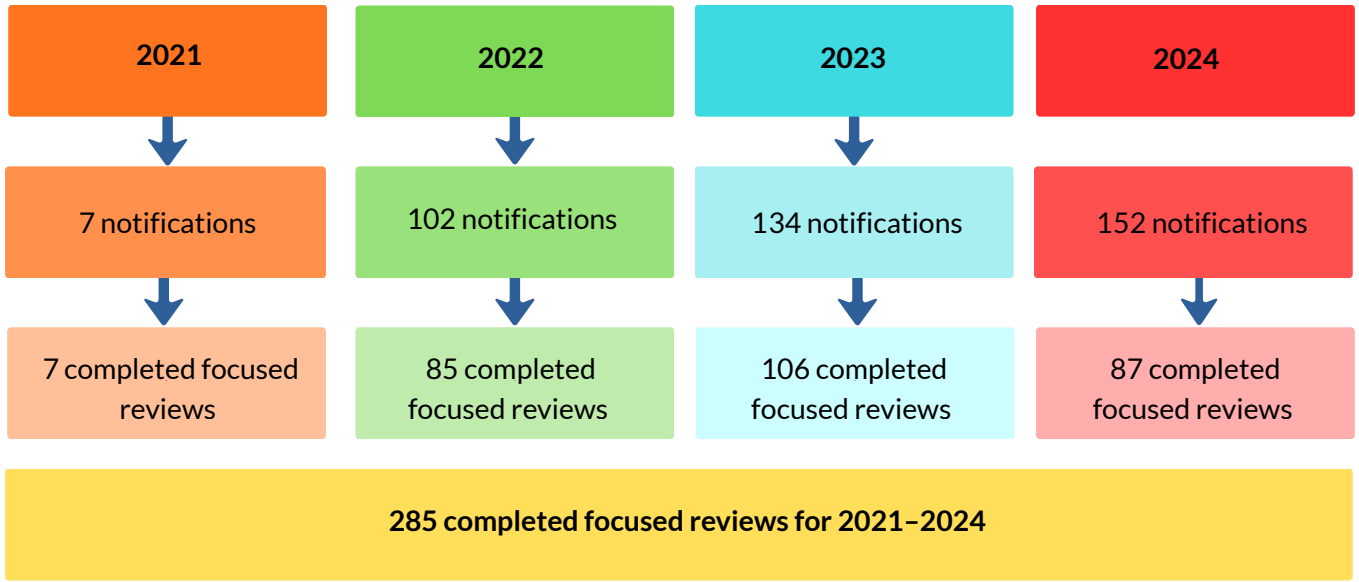
Information included in this chapter

This chapter reports on autistic adults without a learning disability who died between June 2021 and December 2024, and for whom a review was completed by November 2025. All notified deaths in this group receive a focused review. Further detail on the LeDeR process is provided in Appendix 0.1.

NHS England informed us that the difference in notification numbers compared with previous reports is due to the following reasons: In any given year, some deaths are notified to LeDeR relating to people who do not have a learning disability or a clinical diagnosis of autism. These deaths are not reviewed, and the notification data are deleted from the system. A decision was made by NHS England to remove the notification data relating to people who were not eligible for a LeDeR review (i.e. people who do not have a learning disability or a clinical diagnosis of autism, or who had not died), to protect their confidentiality and privacy rights. As a result, the number of notifications reported in the 2024 report is lower than in previous years' reports.

Between 2021 and 2024, 395 deaths of autistic adults without a learning disability were notified to LeDeR. Of these, 285 had a completed focused review that was included in the current analysis (Figure 4.1). Findings are presented for the combined 2021–2024 cohort to provide a sufficiently robust dataset for analysis and to reduce the risk of identification in smaller subgroups. Given the small numbers, formal statistical analysis has not been undertaken, and findings are presented descriptively. However, where available, wider literature is referenced to provide additional context.

Figure 4.1: *Notifications to LeDeR and completed reviews of the deaths of autistic adults without a learning disability*



Due to the small sample size, these findings should not be interpreted as representative of all autistic adults without a learning disability who died in England during this period. Deaths that are sudden, unexpected, or subject to investigation may be more likely to be reported to LeDeR. The data nevertheless offer important insights into mortality patterns and care experiences within a defined cohort, supporting quality improvement and informing future research priorities.

LeDeR notifications for autistic adults without a learning disability 2021-2024

Figure 4.2: *Notifier relationship to the autistic adult who died from 2021-2024*

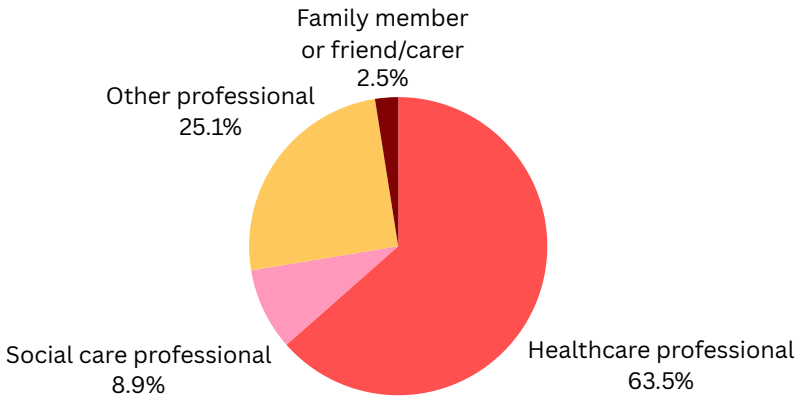
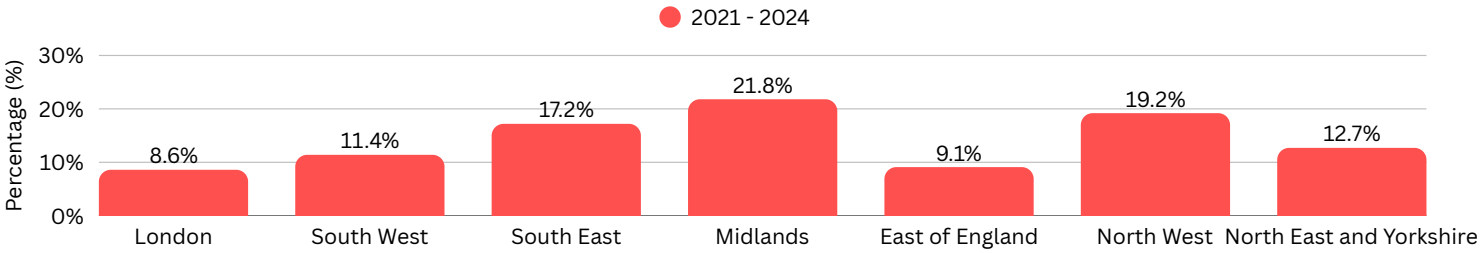


Figure 4.2 shows that from 2021 and 2024, notifications to LeDeR for deaths of autistic adults without a learning disability were predominantly submitted by professionals. Nearly two-thirds of notifications were submitted by healthcare professionals (63.5%).

Notifications were received from all NHS England regions (Figure 4.3). The largest proportions of notifications of autistic adults without a learning disability were from the Midlands (21.8%), the North West of England (19.2%) and the South East of England (17.2%). It should be noted that NHS England regions are not of equal size and population and therefore it would not be anticipated that similar numbers of notifications would be received from each region.

Figure 4.3: *Region of notification for autistic adults without a learning disability notified to LeDeR*



The median age at death for autistic adults without a learning disability notified to LeDeR between 2021 and 2024 was 39.1 years (Table 4.1). When examined by sex registered at birth, the median age at death was 42.4 years for males and 35.2 years for females. These data should be interpreted with caution and are provided for descriptive purposes only.

Several limitations should be considered when interpreting the median age at death for autistic adults without a learning disability reported to LeDeR, and these findings should not be considered representative of all autistic adults who died in England during this period. First, the cohort included only 285 completed focused reviews, which is likely to underestimate the true number of deaths in this population because not all deaths of autistic people are currently notified to LeDeR. Second, deaths among younger adults due to accidents, suicide, or other sudden causes may be more likely to be notified and reviewed than deaths from natural causes, which may contribute to a lower median age at death in the LeDeR data. Third, autism remains underdiagnosed in older adults (O'Nions et al., 2023), meaning fewer older autistic adults are likely to have a recorded diagnosis and therefore fewer may be notified to LeDeR. Together, these factors may contribute to an underestimation of the median age at death. Despite these limitations, wider evidence consistently shows elevated premature mortality among autistic adults, particularly in relation to suicide and epilepsy (O'Nions et al., 2024). Full notification demographics for autistic adults without a learning disability are presented in Appendix 4.1.

Table 4.1: *Median age at death for autistic adults without a learning disability notified to LeDeR*

Sex registered at birth	Median age at death 2021-2024	IQR 2021-2024
Male	42.4	26.4 – 58.0
Female	35.2	24.0 – 49.3
Autistic adults' median age at death	39.1	26.1 – 57.0

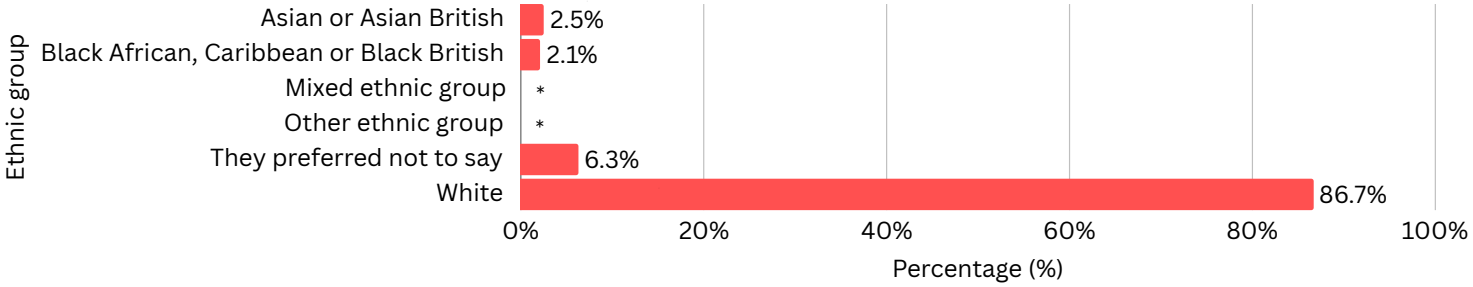
IQR = Interquartile Range

LeDeR reviews for autistic adults without a learning disability 2021-2024

Of the 285 autistic adults without a learning disability who had a completed focused review between 2021 and 2024, 73.0% were male, 23.5% female, and the sex registered at birth of 3.5% was not known. Median age at diagnosis of autism was similar for males and females (31.5 and 31.0 years, respectively). This contrasts with UK research showing much earlier mean diagnosis in childhood (12.3 years for females and 14.9 years for males) (Russell et al., 2022), highlighting under-diagnosis in adults and likely cohort effects related to changes in recognition and diagnostic practices. Overall, these figures suggest that many individuals in this group were diagnosed in adulthood. Further demographic detail is provided in Appendix 4.2.

The majority of autistic adults without a learning disability who had a completed focused review between 2021 and 2024 were from a "White" ethnic group (86.7%), with a small number from the "Asian or Asian British" and "Black, African, Caribbean or Black British" ethnic groups (Figure 4.4). Please note that percentages are not reported where counts are fewer than five, in order to prevent identification.

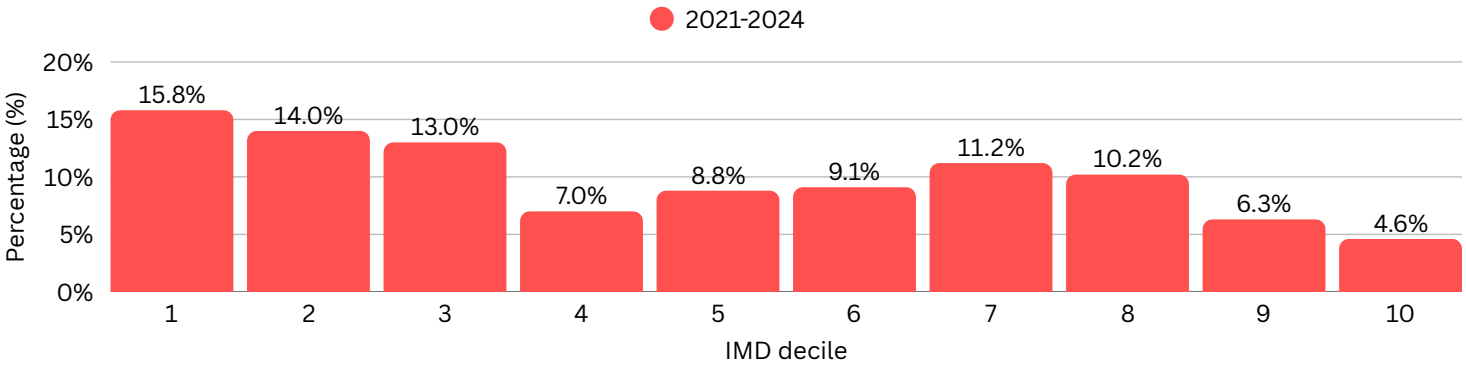
Figure 4.4: *Ethnic group for autistic adults without a learning disability*



*Fewer than five

Figure 4.5 shows the distribution of Index of Multiple Deprivation (IMD) deciles. 29.8% of autistic adults without a learning disability whose deaths were reported to LeDeR lived in the most deprived areas of England (deciles 1 and 2), while 10.9% lived in the least deprived areas (deciles 9 and 10). Although deaths occurred across all deciles, the distribution was weighted towards greater deprivation, reflecting wider social and health inequalities, including barriers to healthcare and support services.

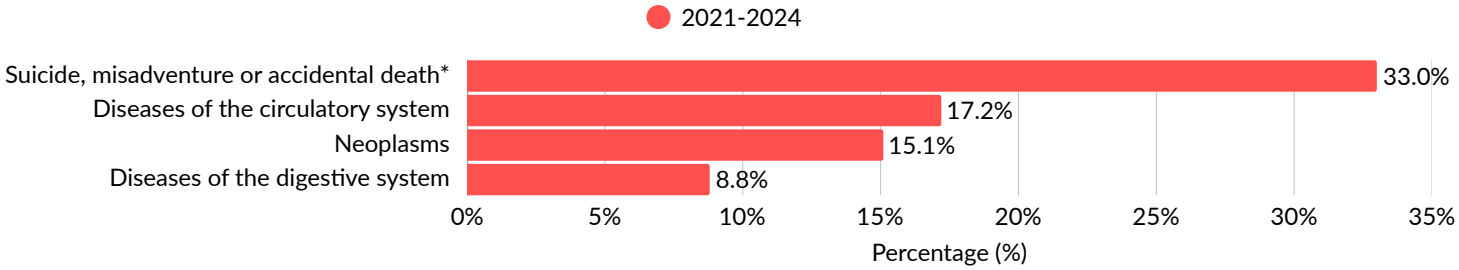
Figure 4.5: *Indices of multiple deprivation for autistic adults without a learning disability*



Causes of death

Out of the 285 reviews for autistic adults without a learning disability, 281 (98.6%) had a known cause of death. Suicide, misadventure, or accidental death was the most common category of cause of death, accounting for approximately one-third of all autistic adults without a learning disability who died between 2021 and 2024 (Figure 4.6, overleaf). Deaths from diseases of the circulatory system (e.g. cardiac arrest or stroke), neoplasms (cancers), and diseases of the digestive system (e.g. perforated bowel) were the next most common causes of death.

Figure 4.6: *Most common ICD-10 grouped causes of death for autistic adults without a learning disability*



*Suicide, misadventure, and accidental death have been grouped because of the way they are reported on the MCCD, where the distinction between causes is not always clearly specified. For more details, see the ONS website.
See Appendix 4.3 for a full list of grouped causes of death.

Circumstances of death

Below, we detail the circumstances surrounding the deaths of autistic adults without a learning disability who died between 2021 and 2024. Most autistic adults without a learning disability died in an acute hospital (40.0%) or at home (35.1%) (Table 4.2). For a more detailed breakdown of circumstances of death, please see Appendices 4.4–4.5.

Table 4.2: *Place of death for autistic adults without a learning disability*

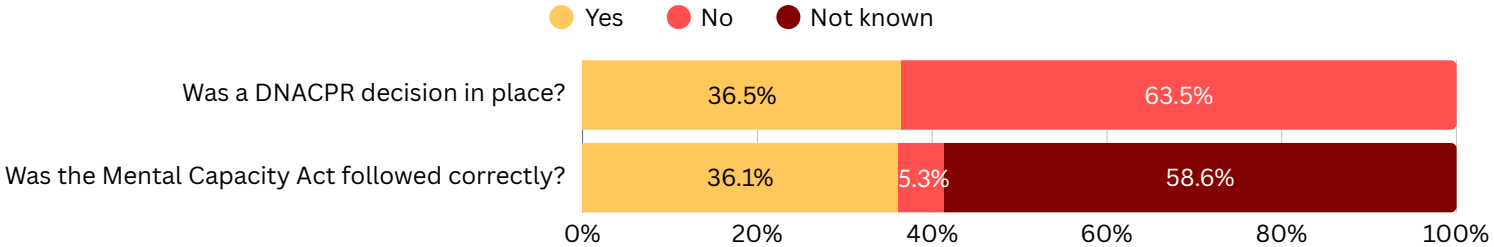
Place of death	2021-2024
Acute hospital	114 (40.0%)
Assessment and treatment unit	0 (0.0%)
Community hospital	*
Home of the person who died	100 (35.1%)
Home of a friend or relative	7 (2.5%)
Residential nursing home	13 (4.6%)
Hospice	7 (2.5%)
Other	39 (13.7%)
Not known	*
Total	285 (100.0%)

*Fewer than five

As shown in Figure 4.7, a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision was recorded in 36.5% of deaths. Among those with a DNACPR decision at death, documentation was correctly completed and followed in around two-thirds of cases (66.3%), while in just over a quarter of cases the status was not known (26.9%) (see Appendix 4.4).

Figure 4.7 also shows that the Mental Capacity Act (MCA) was recorded as correctly followed in 36.1% of autistic adults without a learning disability, although this was reported as not known in a large proportion of reviews (58.6%). This category may include cases where there was insufficient information available to determine whether the Act had been applied, as well as cases where a Mental Capacity Act assessment was not required and should therefore be interpreted with caution.

Figure 4.7: *DNACPR decision and MCA for autistic adults without a learning disability*



More than half of the deaths of autistic adults without a learning disability were known to be reported to a coroner (56.5%). Police investigations were known to be recorded in just under a third (30.5%), while safeguarding concerns were known to be reported in 9.5% (Figure 4.8, overleaf).

Figure 4.8: *Coroner referrals, police investigations, and safeguarding concerns following death for autistic adults without a learning disability*

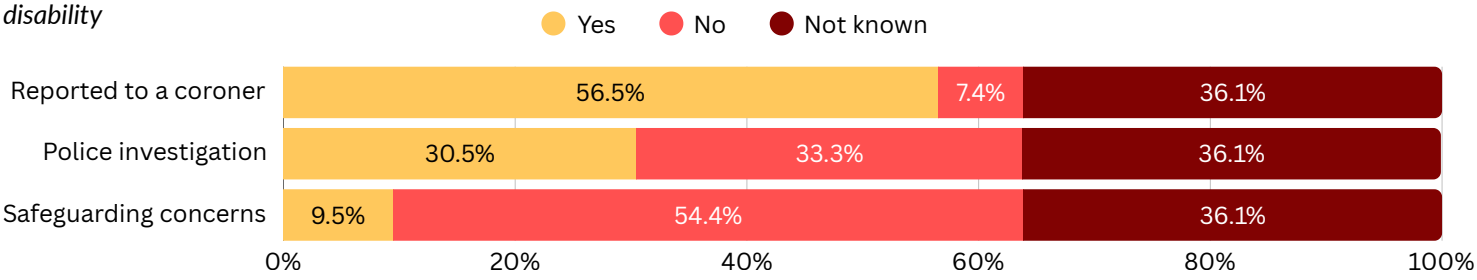
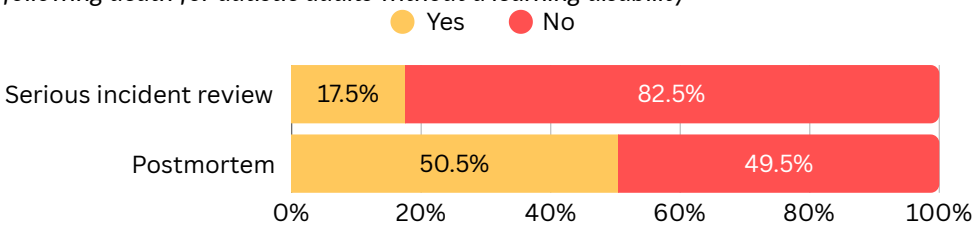


Figure 4.9: *Serious incident reviews and postmortem examinations following death for autistic adults without a learning disability*

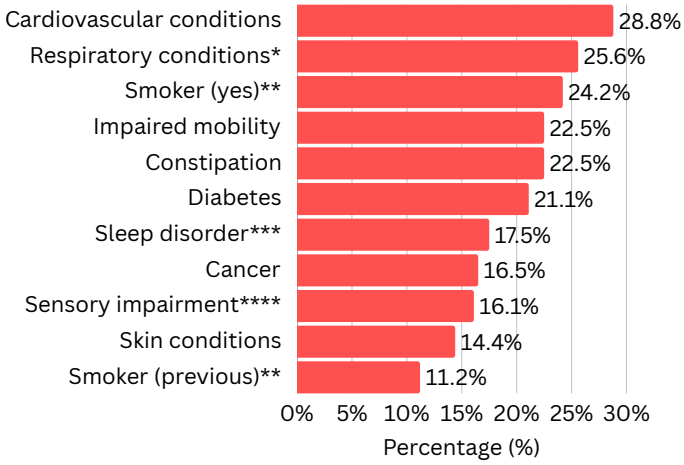


In addition, a serious incident review was carried out for 17.5% of deaths, and postmortem examinations were conducted in around half of the deaths reviewed (50.5%) (Figure 4.9). (See Appendices 4.4–4.5 for more details).

Co-occurring physical and mental health conditions

Figures 4.10 and 4.11 show the most commonly reported co-occurring physical and mental health conditions among autistic adults without a learning disability. These represent co-occurring long-term health conditions identified during the LeDeR review process and should not be interpreted as underlying causes of death. The most commonly occurring physical health conditions were cardiovascular conditions (28.8%) and respiratory conditions including COVID-19 (25.6%). Around a quarter were reported to be current smokers (24.2%), and similar proportions had impaired mobility (22.5%) or constipation (22.5%). See Appendix 4.6 for a full list of physical health conditions.

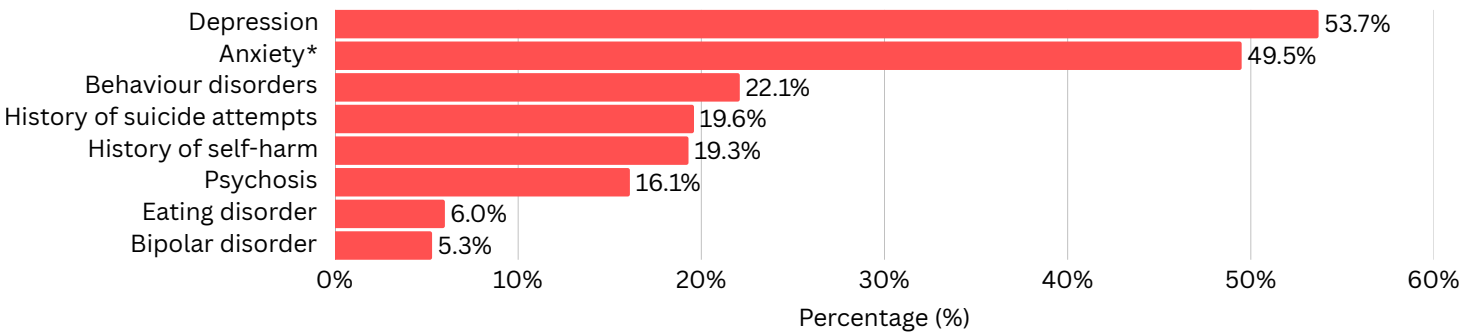
Figure 4.10: *Most common co-occurring physical health conditions for autistic adults without a learning disability*



*Including COVID-19.
**Whilst smoking is not a physical health comorbidity itself, it is known to be linked to several physical health conditions and is therefore presented here.
***Sleep disorders can refer to any disorder related to sleep, e.g. insomnia, sleep apnoea, etc.
**** Sensory impairment refers to impairments in hearing and/or vision.

In the 285 focused reviews of autistic adults without a learning disability, depression (53.7%) and anxiety (49.5%) were commonly reported. Other reported mental health conditions and related factors included behavioural disorders (22.1%), a history of suicide attempts (19.6%), and self-harm (19.3%) (Figure 4.11). Self-harm and suicide attempts are included as clinically relevant factors associated with mental health and increased risk, rather than as formal diagnostic conditions.

Figure 4.11: *Most common mental health conditions and related factors for autistic adults without a learning disability*



*Anxiety includes anxiety disorder, obsessive compulsive disorder, social anxiety disorder, phobias and post-traumatic stress disorder.

Mental health support and medication

In the 285 focused reviews of autistic adults without a learning disability, recorded mental health conditions were more common than documented prescribing of anti-depressant or anti-anxiety medication. This may reflect that recorded conditions included both current and past diagnoses and do not necessarily require active treatment at the time of death.

Table 4.3 shows that 44.9% of all autistic adults without a learning disability were offered talking therapy support (e.g. CBT, group therapy, psychotherapy, or counselling), compared with 75.5% of those who died by suicide, misadventure, or accidental death (please see Appendix 4.7 for findings relating to deaths by suicide only). However, it is unclear whether therapy was offered before the death event and, if so, how close this was to the time of death, whether individuals engaged with or completed treatment, or whether therapies were adapted for autistic adults, limiting interpretation. The higher proportion of autistic adults without a learning disability who died by suicide, misadventure or accidental death and were offered talking therapies may suggest that mental health needs had been recognised and support attempted. Nevertheless, these findings raise important questions about the accessibility, suitability, and effectiveness of mental health interventions for autistic adults without a learning disability experiencing significant distress or risk. This is particularly relevant in light of recent evidence of increased suicide risk among autistic people and challenges engaging with standard talking therapies (Brown et al., 2024; El Baou et al., 2023).

Table 4.3: *Mental health support offered for autistic adults without a learning disability*

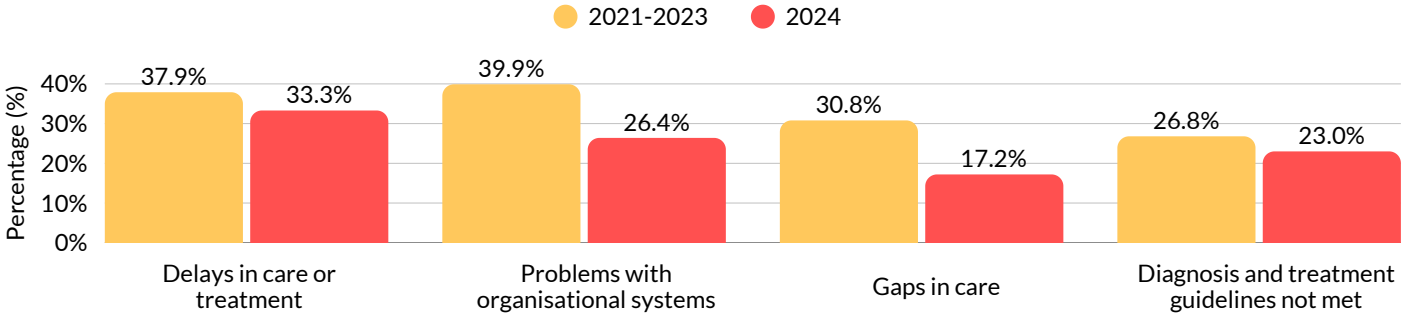
Mental health support	All deaths	Death by suicide, misadventure, or accidental death
History of mental health medication*		
Anti-depressant prescription	159 (55.8%)	53 (56.4%)
Anti-psychotic prescription	92 (32.3%)	9 (9.6%)
Anti-anxiety prescription	102 (35.8%)	47 (50.0%)
Talking therapies offered		
Yes	128 (44.9%)	71 (75.5%)
No	80 (28.1%)	7 (7.4%)
Not known	77 (27.0%)	16 (17.0%)
Total	285 (100.0%)	94 (100.0%)

*Note that some anti-depressants (e.g. SSRIs) can also be used to treat anxiety with or without depression and may have been recorded as either an anti-depressant or anti-anxiety medication in the focused LeDeR review.

Quality of care

Figure 4.12 shows the proportion of focused reviews for autistic adults without a learning disability that identified problems in care. Across all categories, a smaller proportion of issues were identified in 2024 than in the previous years grouped (2021-2023), with the largest reductions in organisational problems (39.9% vs 26.4%) and gaps in care (30.8% vs 17.2%). Smaller decreases were seen in delays in care or treatment (37.9% vs 33.3%) and unmet diagnosis and treatment guidelines (26.8% vs 23.0%). However, the number of reviews in earlier years, particularly 2021, was smaller, which may impact the 2021–2023 figures and limit comparability. Overall, these findings suggest a potential improvement in the quality of care received by autistic adults without a learning disability, although some problems with care outlined in the next section remain.

Figure 4.12: *Problems in care for autistic adults without a learning disability*



Summary of problems with specific aspects of care for autistic adults without a learning disability

Problems with care were, in many cases, interrelated across all four quality of care indicators. Delays in recognising individuals' needs often resulted in gaps in health and social care, such as missed follow-ups or unmanaged risks. Poor coordination between services further contributed to delays and gaps, especially when information was not shared or when there was a lack of multiagency, multidisciplinary team (MDT) approaches. When services and care were not tailored to meet the person's needs, many individuals disengaged from services, affecting the continuity of treatment and health and social care. Across all four areas, factors such as limited provision of reasonable adjustments, poor communication, and a lack of coordinated health and social care influenced both how care was delivered and how it was experienced.

Figure 4.13: *Qualitative framework analysis of problems with health and social care for autistic adults without a learning disability*

Summary and Discussion

Between 2021 and 2024, 395 deaths of autistic adults without a learning disability were notified to LeDeR, of which 285 had a completed focused review at the time of analysis. These figures represent a growing dataset compared to previous years; however, findings should not be interpreted as representative of all autistic adults without a learning disability who died in England during this period.

The demographic profile of autistic adults without a learning disability whose deaths were reviewed remained broadly consistent with previous reporting. Most were male, and most were recorded as being from a “White" ethnic background. Nearly one-third resided in the most deprived areas of England. The median age at death of those notified to LeDeR was 39.1 years. However, this should not be interpreted as life expectancy. Wider evidence has shown elevated premature mortality in autistic adults, particularly in relation to mental health conditions, suicide and epilepsy (O’Nions et al., 2024). The age at death findings within LeDeR are also affected by reporting patterns, diagnostic skew towards younger cohorts, and the likelihood that sudden or unexpected deaths are more often reported to LeDeR, all of which will likely affect the age data. Nonetheless, the relatively young age profile of deaths in this cohort warrants continued attention. Improved reporting practices and broader notifications of deaths to LeDeR are important to support more representative future analyses of mortality and health inequalities experienced by autistic adults.

The median age at autism diagnosis identified in completed LeDeR reviews for autistic people without a learning disability was 32 years, with little difference between males and females, indicating that many individuals in this cohort were diagnosed in adulthood. This contrasts with population-level evidence suggesting that autism is more commonly diagnosed at a younger age during childhood or adolescence (Russell et al., 2022). The older age at diagnosis within the LeDeR cohort likely reflects several factors, including, historical under-recognition of autism, changing diagnostic criteria and service access over time, and the increasing identification of autism in adulthood (Stewart & Happé, 2025). However, it is also likely to reflect sampling bias within deaths notified to LeDeR, as under-reporting remains a key limitation of the dataset.

Many deaths occurred in a hospital or at home. More than half were reported to a coroner, around one third were involved in a police investigation and around half were involved in a postmortem examination. This pattern likely reflects the relatively high proportion of sudden, unexpected, or externally caused deaths notified to LeDeR.

Mental health conditions were common, and depression and anxiety affected around half of the cohort. Nearly one-fifth had a recorded history of suicide attempts or self-harm; and suicide, misadventure, or accidental death remained the most common grouped underlying cause of death, accounting for one-third of reviewed deaths. This is consistent with previous LeDeR findings (White et al., 2025) and aligns with international evidence demonstrating elevated suicide risk among autistic adults without a learning disability (Hirvikoski et al., 2016). A substantial proportion of those who died by suicide had previously been prescribed mental health medication or accessed talking therapies. While this indicates input from services, the data do not allow conclusions about the suitability, adaptability, or effectiveness of the support provided. However, we identified potential service and treatment-related issues that may be relevant. These include delays in recognising an autistic adult's needs, poor coordination between services, particularly mental health services, limited reasonable adjustments and poor communication and information sharing both between services and with autistic adults themselves.

The quality-of-care data suggest a small improvement in 2024 compared to 2021-2023. Across all four areas examined, fewer focused reviews of autistic adults without a learning disability identified problems with care in 2024. The largest reductions were seen in problems with organisational systems and gaps in care. However, no formal statistical comparisons were undertaken because of the small sample sizes in this chapter, and findings should be interpreted cautiously as they may not be representative of all deaths of autistic adults without a learning disability. Furthermore, the qualitative analysis suggests a more complex picture. While fewer problems with care were identified overall, the nature and pattern of issues remain. This suggests that, despite improvement in reporting of problems with care, underlying challenges in accessing timely, appropriate, and coordinated care persist for autistic adults without a learning disability.

While the number of notifications has increased over time, under-reporting remains a limitation, and more representative data in future analyses will help to ensure generalisable findings.

Looking forward

Priorities for health and care services:

1. Improve suicide prevention in autistic people

- At the healthcare level:
  - Pathways for autistic individuals who require mental health support should be accessible and responsive. Clinicians should be able to recognise non-typical signs of distress and be prepared to offer further support around key transition periods such as change in accommodation or education/work.
  - Where necessary, review existing crisis service accessibility and upskill professionals in neurodiversity-informed care and different presentations of distress.
  - Reasonable adjustments for autistic adults without a learning disability should be embedded into care pathways, including adaptations to communication, appointment structures, talking therapies and the physical environment as necessary.
  - Mental healthcare providers should ensure crisis and safety plans are clear, personalised, and appropriately shared across the person's care network, especially for those with a history of self-harm or suicidal ideation.
- At the policy level:
  - Although recognised as a priority group in the NHSE suicide prevention strategy, a targeted action plan to prevent suicide in autistic people should be considered, incorporating factors identified by LeDeR such as limited reasonable adjustments, poor communication, and a lack of coordinated care.
  - Improved data on deaths of autistic people without a learning disability must be addressed at a national level. Without suitable data, the impact of improved services cannot be determined.

2. Address gaps in understanding of and provision for the needs of autistic adults without a learning disability

- At the healthcare level:
  - Address disparities in access to autism diagnostic assessments to mitigate the risks associated with undiagnosed autism, with provision of appropriate post-diagnostic support.
  - Ensure use of the reasonable adjustments flag to identify autistic individuals to address care inequalities, and identify individuals who may need additional support to access timely healthcare.

For research:

1. Mental health and suicide prevention research:

- Develop and test autism-specific suicide prevention interventions, including autism-adapted risk management strategies, safety planning, and autism-adapted mental health care and talking therapies to meet the needs of autistic people and improve engagement and outcomes. Research on the type of therapies best suited to autistic people to reduce suicide risk is also required.
- There is limited understanding of how suicide risk in autistic people evolves across life stages. This requires longitudinal studies exploring diagnosis timing, mental health trajectories, service access and outcomes, and transitions, e.g. from education to adulthood.
- Identify autism-specific risk and protective factors contributing to suicidal thoughts and acts in autistic adults without a learning disability, including experience of trauma and bullying; mental health; social factors such as social isolation, support and employment; and the role of peer support and diagnosis timing to move beyond general population models and inform risk detection.
- Given evidence of barriers to care, but limited evidence on how to fix systems, co-produced research is needed to inform service re-design, access and system-level interventions. These could include autism-adapted crisis pathways, intensive support, continuity-of-care and integrated care models, as well as studying the impact of reasonable adjustments (including the reasonable adjustment digital flag) and early vs. late diagnosis.

2. More research is also required to understand the health and ageing trajectory of autistic adults, including potential differences in patterns of health and illness and the services needed to meet their changing needs.

- This may include symptoms that are not clearly understood, such as gastrointestinal issues, chronic pain, fatigue or hypermobility, as they may contribute to overall illness burden, service use and quality of life.

Chapter 5

Deep Dives and Publications that have arisen from LeDeR

The LeDeR academic partnership, led by King's College London in collaboration with NHS England, undertakes targeted deep dives into key themes arising from LeDeR reviews. These deep dives use quantitative and qualitative methods to generate knowledge that can inform actionable improvements in care.

This chapter summarises four recent deep dives into issues affecting the care of people with a learning disability: Avoidable Cancer, DNACPR, Genetic Conditions, and Barriers to Vaccination. Full reports are available on the Learning from Lives and Deaths – people with a learning disability and autistic people (LeDeR) website.

Avoidable Cancer

This deep dive used a quantitative observational design drawing on LeDeR reviews of adults with a learning disability who died from cancer in 2021 and 2022. The analysis included all eligible deaths identified using ICD-10 codes for neoplasms, with a defined subsample of deaths classified as avoidable using the Organisation for Economic Co-operation and Development (OECD) framework. The study combined analysis of data from initial and focused LeDeR reviews to examine causes of death, demographics, and circumstances of care, alongside additional information on screening, investigations, treatment, and medications for a subset of cases. This approach enabled a comprehensive assessment of avoidable cancer mortality patterns and cancer care pathways.

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

This deep dive used a mixed-methods approach drawing on LeDeR reviews of deaths in England between 2020 and 2022 to examine why cardiopulmonary resuscitation (CPR) is sometimes attempted despite an active DNACPR recommendation. The study involved systematic screening of completed LeDeR reviews to identify cases where DNACPR decisions were incorrectly documented or were not followed. These cases then underwent detailed case review and qualitative analysis to explore underlying factors such as communication and decision-making processes. This approach enabled an in-depth examination of how DNACPR recommendations are recorded, shared, and acted upon across care settings. The deep dive has been developed into an academic manuscript, which is available here.

Genetic Conditions (under production)

This deep dive used a quantitative analytical approach drawing on LeDeR reviews of deaths in 2021–2022 to examine how congenital malformations, chromosomal abnormalities, and genetic conditions (ICD-10 "Q" codes) are recorded on the Medical Certificate of Cause of Death (MCCD), and whether care differs for this group. The study used initial reviews to describe demographic characteristics and patterns of death certification and focused reviews to examine care quality. Comparisons were made between people with and without a "Q" code recorded, with analyses adjusting for age, sex, and ethnicity to explore differences in quality of care indicators. This approach enabled examination of how genetic conditions are recorded on the MCCD, alongside associated comorbidities and care experiences.

Barriers to Vaccination (under production)

This deep dive used a mixed-methods approach, combining a systematic review and a qualitative study to explore barriers and facilitators to respiratory vaccination among people with a learning disability. The systematic review followed Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidance, with studies identified through comprehensive database searches, screened independently, and synthesised using a structured narrative approach with quality appraisal. The qualitative study was co-produced with people with a learning disability and involved focus groups and interviews with individuals and caregivers, using flexible and accessible methods. Data were analysed using reflexive thematic analysis. Together, these approaches enabled examination of both published evidence and lived experiences of accessing vaccination.

References

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References

- Antonarakis, S. E., Skotko, B. G., Rafii, M. S., Strydom, A., Pape, S. E., Bianchi, D. W., Sherman, S. L., & Reeves, R. H. (2020). Down syndrome. *Nature Reviews Disease Primers, 6*, 9. https://doi.org/10.1038/s41572-019-0143-7

- Baksh, R. A., Strydom, A., Pape, S. E., Chan, L. F., & Gulliford, M. C. (2022). Susceptibility to COVID-19 diagnosis in people with Down syndrome compared to the general population: A matched cohort study using primary care electronic records in the UK. *Journal of General Internal Medicine, 37*(8), 2009–2015. https://doi.org/10.1007/s11606-022-07420-9

- British Psychological Society. (2025). *Dementia and people with intellectual disabilities: Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia.* British Psychological Society. https://www.bps.org.uk/guideline/dementia-and-people-intellectual-disabilities-0

- Brown, C. M., Newell, V., Sahin, E., & Hedley, D. (2024). Updated systematic review of suicide in autism: 2018–2024. *Current Developmental Disorders Reports, 11*(4), 225–256. https://doi.org/10.1007/s40474-024-00308-9

- Corniello, Clarissa, et al. "Diagnosis and treatment of late-onset myoclonic epilepsy in Down syndrome (LOMEDS): A systematic review with individual patients' data analysis." *Seizure: European Journal of Epilepsy 109* (2023): 62-67. https://doi.org/10.1016/j.seizure.2023.05.017

- Department of Health and Social Care. (2001). *Valuing people: A new strategy for learning disability for the 21st century.* Gov.uk. https://assets.publishing.service.gov.uk/media/5a7b854740f0b62826a041b9/5086.pdf

- Department of Health and Social Care. (2023). *Death certification reform and the introduction of medical examiners.* GOV.UK. https://www.gov.uk/government/collections/death-certification-reform-and-the-introduction-of-medical-examiners

- El Baou, C., Bell, G., Saunders, R., Buckman, J. E. J., Mandy, W., Dagnan, D., O'Nions, E., Pender, R., Clements, H., Pilling, S., Richards, M., John, A., & Stott, J. (2023). Effectiveness of primary care psychological therapy services for treating depression and anxiety in autistic adults in England: A retrospective, matched, observational cohort study of national health-care records. *The Lancet Psychiatry, 10*(12), 944–954. https://doi.org/10.1016/S2215-0366(23)00291-2

- Emerson, E., Baines, S., Allerton, L., & Welch, V. (2011). *Health inequalities and people with learning disabilities in the UK: 2012.* Improving Health and Lives: Learning Disabilities Observatory. https://www.choiceforum.org/docs/ineqer.pdf

- Heslop, P., Blair, P. S., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2014). *The confidential inquiry into premature deaths of people with intellectual disabilities (CIPOLD).* Lancet, 383(9920), 889–895. https://doi.org/10.1016/s0140-6736(13)62026-7

- Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208(3), 232–238. https://doi.org/10.1192/bjp.bp.114.160192

- Illouz, T., Biragyn, A., Iulita, M. F., et al. (2021). Immune dysregulation and the increased risk of complications and mortality following respiratory tract infections in adults with Down syndrome. Frontiers in Immunology, 12, 621440. https://doi.org/10.3389/fimmu.2021.621440

- OECD. (2022). *Avoidable mortality: OECD/Eurostat lists of preventable and treatable causes of death (January 2022 version).* Organisation for Economic Co-operation and Development. https://www.oecd.org/content/dam/oecd/en/data/datasets/oecd-health-statistics/avoidable-mortality-2019-joint-oecd-eurostat-list-preventable-treatable-causes-of-death.pdf

- Office for National Statistics. (2023). *Deaths registered weekly in England and Wales, provisional: Week ending 30 December 2022.* https://www.ons.gov.uk/releases/deathsregisteredweeklyinenglandandwalesprovisionalweekending30december2022

References

- Office for National Statistics. (2025a). Mortality statistics - underlying cause, sex and age www.nomisweb.co.uk/query/construct/summary.asp?mode=construct&version=0&dataset=161
- Office for National Statistics. (2025b). Safeguarding adults, England, 2024 to 2025 https://www.gov.uk/government/statistics/safeguarding-adults-england-2024-to-2025
- O'Nions, E., Petersen, I., Buckman, J. E. J., Charlton, J., Baxter, H., McManus, S., David, A. S., Brugha, T., Happé, F., & Lewer, D. (2024). Estimating life expectancy and years of life lost for autistic people in the UK: A matched cohort study. *The Lancet Regional Health – Europe*, *29*, 100629. https://doi.org/10.1016/j.lanepe.2023.100629
- O'Nions, E., Petersen, I., Buckman, J. E. J., Charlton, R., Cooper, C., Corbett, A., Happé, F., Manthorpe, J., Richards, M., Saunders, R., Zanker, C., Mandy, W., & Stott, J. (2023). Autism in England: Assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data. *The Lancet Regional Health: Europe*, *29*, Article 100626. https://doi.org/10.1016/j.lanepe.2023.100626
- Patel, D. R., Demma Cabral, M., Ho, A., & Merrick, J. (2020). A clinical primer on intellectual disability. *Translational Pediatrics*, *9*(Suppl. 1), S23–S35. https://doi.org/10.21037/tp.2020.02.02
- Ramsay, M. (Ed.). (2020). *Immunisation against infectious disease.* UK Health Security Agency. https://www.gov.uk/government/collections/immunisation-against-infectious-disease-the-green-book
- Royal College of Psychiatrists. (2017). *Management of epilepsy in adults with intellectual disability (College Report CR203).* Royal College of Psychiatrists. https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr203.pdf?sfvrsn=c534ff08_2
- Russell, G., Stapley, S., Newlove-Delgado, T., Salmon, A., White, R., Warren, F., Pearson, A., & Ford, T. (2022). Time trends in autism diagnosis over 20 years: A UK population-based cohort study. Journal of Child Psychology and Psychiatry, 63(6), 674–682. https://doi.org/10.1111/jcpp.13505
- Shankar, R., Henley, W. E., Alauddin, S., Watkins, L. V., Tromans, S. J., Laugharne, R. A., McLean, B., & Heslop, P. (2026). Epilepsy-related premature mortality in adults with intellectual disability in England: A population-based analysis. Journal of Neurology, Neurosurgery, and Psychiatry, 97(4), 325. https://doi.org/10.1136/jnnp-2025-337291
- Stewart, G. R., & Happé, F. (2025). Aging across the autism spectrum. *Annual Review of Developmental Psychology*, *7*(1), 461–484. https://www.annualreviews.org/content/journals/10.1146/annurev-devpsych-111323-090813
- Sun, J. J., Watkins, L., Henley, W., Laugharne, R., Angus-Leppan, H., Sawhney, I., Shahidi, M. M., Purandare, K., Eyeoyibo, M., Scheepers, M., Lines, G., Winterhalder, R., Perera, B., Hyams, B., Ashby, S., & Shankar, R. (2023). Mortality risk in adults with intellectual disabilities and epilepsy: an England and Wales case-control study. J Neurol, 270(7), 3527-3536. https://doi.org/10.1007/s00415-023-11701-6
- UK Covid-19 Inquiry. *INQ000587296 - Expert Report for the UK Covid 19 Public Inquiry by Professor Chris Hatton and Professor Richard Hastings titled Module 6: The impact of the Covid 19 pandemic on the publicly and privately funded adult social care sector in England, Wales, Scotland and Northern Ireland, dated 03/04/2025 UK Covid-19 Inquiry Archives.* (2025, July 28). UK Covid-19 Inquiry. https://covid19.public-inquiry.uk/documents/inq000587296-expert-report-for-the-uk-covid-19-public-inquiry-by-professor-chris-hatton-and-professor-richard-hastings-titled-module-6-the-impact-of-the-covid-19-pandemic-on-the-publicly-and-privat/
- UK Health Security Agency. (2024a). *Heat mortality monitoring report: 2022.* UK Health Security Agency. https://www.gov.uk/government/publications/heat-mortality-monitoring-reports/heat-mortality-monitoring-report-2022
- UK Health Security Agency. (2024b). *Surveillance of influenza and other seasonal respiratory viruses in the UK, winter 2022 to 2023.* https://www.gov.uk/government/statistics/annual-flu-reports/surveillance-of-influenza-and-other-seasonal-respiratory-viruses-in-the-uk-winter-2022-to-2023
- UK Parliament. (2022). *Down Syndrome Act 2022.* https://www.legislation.gov.uk/ukpga/2022/18/contents/enacted

References

- van Timmeren, E. A., Waninge, A., van Schrojenstein Lantman-de Valk, H. M. J., van der Putten, A. A. J., & van der Schans, C. P. (2017). Patterns of multimorbidity in people with severe or profound intellectual and motor disabilities. *Research in Developmental Disabilities*, *67*, 28–33. https://doi.org/10.1016/j.ridd.2017.05.002

- White, A., Roberts, C., Ding, J., Sheehan, R., Sanger, E., Chauhan, U., & Strydom, A. (2024). *Deaths due to pneumonia in people with a learning disability*. https://www.kcl.ac.uk/ioppn/assets/fans-dept/deaths-due-to-pneumonia-in-people-with-a-learning-disability-leder-report-2024.pdf

- White, A., Sheehan, R., Ding, J., Roberts, C., Magill, N., Keagan-Bull, R., Carter, B., Chauhan, U., Tuffrey-Wijne, I., & Strydom, A. (2023). *LeDeR annual report: Learning from lives and deaths: People with a learning disability and autistic people*. https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-2022-v2.0.pdf

- White, A., Sheehan, R., Ditzel, N., Ding, J., Roberts, C., Magill, N., Yu, M. C. L., Keagan-Bull, R., Chauhan, U., Tuffrey-Wijne, I., & Strydom, A. (2025). *Learning from the lives and deaths: People with a learning disability and autistic people (2023)*. https://www.kcl.ac.uk/ioppn/assets/pdfs/leder/leder-annual-report-2023.pdf

- World Health Organization. (n.d.). *ICD-10 version 2019*. Retrieved March 18, 2026, from https://icd.who.int/browse10/2019/en#/F70-F79

- World Health Organization. (2023). *ICD-11: International classification of diseases (11th ed.)*. https://icd.who.int/en