Appendices

LeDeR

Annual Report 2024

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

2024 LeDeR Appendix

Appendix 0.1: *List of Professional Terms*

Key Terms	Explanation
Autism	A lifelong neurodevelopmental condition characterised by differences in social communication, social interaction, sensory processing, and patterns of behaviour. For further information on Autism, please see: What is autism? - NHS
Avoidable mortality/ death	Deaths considered either preventable or treatable in people aged under 75 years, based on the Organisation for Economic Co-operation and Development/Eurostat list of causes of death. For further information on avoidable death, please see: Health at a Glance 2025 Organisation for Economic Co-operation and Development Indicators Our analysis utilised Office for National Statistics (ONS) data for adults aged 20 years and over. In addition, under the OECD framework for avoidable mortality, we classified ICD-10 code U50.9 (death due to assault) as an avoidable death. We also applied the allocation of 0.5 deaths between the preventable and treatable mortality categories where applicable, whereas the published ONS figures are rounded. Furthermore, ONS periodically updates causes of death. This may be particularly relevant for cases coded as U50.9 (assault), where the final cause of death may be revised following the outcome of a coroner's investigation. Our data extract was performed on 25 November 2025. Therefore, our figures for avoidable deaths may differ slightly from the current ONS dataset. Avoidable mortality in England and Wales: 2024
Coded data	A team employed by South Central and West Commissioning Support Unit has reviewed completed initial and focused reviews, coding information using an agreed framework. This includes extracting a wide range of data including both physical and mental health conditions from the free-text sections of the review forms. As coding can only be undertaken once reviews are completed, more recent reviews are less likely to have coded data available.
Cognitive impairment	Cognitive impairment refers to difficulties with mental processes such as memory, attention, understanding, and decision-making, which can affect a person's ability to carry out everyday activities.
Concerns expressed	Concerns expressed is one of the questions considered as part of the LeDeR review process. It refers to cases where concerns about the death were raised during the review by any party involved, including the notifier, reviewer, carers, or professionals involved in the person's care.
Deaths investigated by police	Deaths referred to or investigated by police, potentially where the circumstances are suspicious or to rule out criminal intent or negligence.
Deaths reported to a coroner	Deaths referred for legal investigation, for example where the cause is unknown, the death is violent or unnatural (including accidents or potentially care-related factors), or the person died while detained under state detention (What to do after someone dies: When a death is reported to a coroner - GOV.UK). Reporting status may be recorded in the review, although outcomes may only become available later. Reporting itself does not necessarily indicate poor quality of care.
Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)	A clinical decision that Cardiopulmonary Resuscitation (CPR) should not be attempted if a person's heart or breathing stops.
Down syndrome	Down syndrome is a genetic condition caused by the presence of an extra copy of chromosome 21. It is typically associated with a learning disability and an increased risk of some specific health conditions compared with other adults with a learning disability. For further information on Down syndrome, please see: Down's syndrome - NHS

Ethnic groups	Ethnic group is reported in this report using categories aligned with national standardised ethnicity recording. In LeDeR, this has historically reflected NHS Data Dictionary categories based on the 2001 Census. Where data are available, ethnic group is reported using the five high level categories: · Asian or Asian British · Black, African, Caribbean or Black British · Mixed or Multiple ethnic groups · Other ethnic groups · White
Focused review	An in-depth LeDeR review that examines the person's life, care, and death in greater detail than an initial review to identify learning. A focused review is undertaken for selected cases, including autistic adults without a learning disability; people from ethnic minority groups; people who had been in a detained criminal justice setting or subject to Mental Health Act restrictions within five years of death; cases where there is likely to be significant learning; where families request a focused review; or where concerns have been raised about the care the person received. Focused reviews involve gathering additional information from records, families, professionals, and sources such as coroner reports, and include judgements on care and clear learning points which are used to inform local and national service improvements.
Good practice	Good practice is one of the questions considered as part of the LeDeR review process. It refers to positive practices identified by reviewers that benefited the individual and could also benefit others if adopted more widely. In this report, good practice is used as an indicator of care quality, although whether it is identified depends on the information available to reviewers at the time of the review.
Index of Multiple Deprivation (IMD)	An area-based measure of socioeconomic deprivation in England, combining indicators such as income, employment, health, education, and housing. Areas are ranked into deciles, where decile 1 = most deprived and decile 10 = least deprived. For further information, please see: English indices of deprivation - GOV.UK
Initial review	The first stage of a LeDeR review. When confirmed as in scope of LeDeR, the case is allocated by the Integrated Care Board (ICB), the NHS body responsible for commissioning local health services, to a trained reviewer, who completes an initial review by gathering information from family, professionals, and the health and social care records to build a picture of the person's life, care, and death. For further information, please see: Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy 2021 and Integrated Care Boards (ICBs) – NHS England
International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10)	The 10th revision of the International Classification of Diseases, published by the World Health Organization (WHO), used to classify causes of death and disease categories.
Learning disability	The Department for Health and Social Care (DHSC) (2001) defines a learning disability as: *"a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood"* (DHSC, 2001. p14) Learning disability - applying All Our Health - GOV.UK
LeDeR	Learning from lives and deaths – people with a learning disability and autistic people (LeDeR) refers to a local service improvement initiative in England that enables ICBs to review the deaths of adults with a learning disability and autistic people. LeDeR was established to identify learning from deaths to improve the quality of care, reduce health inequalities and prevent premature mortality. LeDeR operates through a structured review process, including notification, initial review and, where appropriate, a more in-depth focused review. Findings from LeDeR reviews are used to inform local and national service improvement and policy development, reflecting a broader policy commitment to addressing longstanding inequalities in access to healthcare and outcomes for people with a learning disability and autistic people. Further information on LeDeR can be found here: NHS England » Learning from lives and deaths – people with a learning disability and autistic people (LeDeR)

Medical Certificate of Cause of Death (MCCD)	The formal document used to record the medical cause of death. It is completed by a registered medical practitioner who attended the person who died during their lifetime and is able to state the cause of death to the best of their knowledge and belief. A medical examiner provides independent scrutiny of the cause of death for non-coronial deaths. It may be unavailable due to coroner or police involvement or other ongoing investigations.
Mental Capacity Act 2005 (MCA)	The legal framework in England and Wales used to guide decisions when a person may lack capacity to make specific decisions for themselves.
Mental Capacity Act (MCA) compliance	Appropriate application of the Mental Capacity Act, including proper assessment of decision-making capacity and lawful best-interest processes where relevant.
Mild or moderate learning disability	A subgroup of learning disability associated with lower support needs than severe or profound learning disability but still linked to marked health inequalities. Mild learning disability is associated with significant limitations in intellectual and adaptive functioning, although the person may be able to develop a range of practical, communication, social and independent living skills. Support may be required with more complex information, decision-making, education, employment, relationships, finances, healthcare and other aspects of everyday life. Moderate learning disability is associated with more marked limitations in intellectual and adaptive functioning. The person is likely to require regular support with learning, communication, social participation and practical daily living activities, although abilities and support needs will vary considerably between individuals.
Preventable (avoidable) mortality/ death(s)	Deaths that could potentially be avoided (prevented) through effective public health and primary prevention measures, such as vaccination, screening, and lifestyle interventions. For example, deaths from lung cancer due to smoking, measles deaths prevented by vaccination, or heart diseases linked to poor diet and physical activity. Some causes of death are classified as both preventable and treatable under the OECD/Eurostat methodology and are therefore allocated equally between the two categories, which may result in counts including 0.5.
Severe or profound learning disability	A subgroup of learning disability associated with high support needs, often including communication difficulties, mobility limitations, congenital conditions, and complex multimorbidity. Severe learning disability is characterised by very limited verbal communication and a substantial need for support with daily living. Some capacity for functional communication and participation in routine activities may be present with consistent assistance. Profound learning disability is characterised by very significant limitations across communication, self-care, and mobility, requiring continuous support in all areas of daily life. It is frequently associated with congenital conditions, neurological impairments, and co-occurring physical disabilities.
Survival Curve	A graph showing the proportion of adults with a learning disability surviving to different ages, based on deaths reported to LeDeR.
The Staying Alive and Well Group	A team including people with a learning disability and autistic adults with a learning disability to increase connections with the wider community of people with a learning disability and autism, raise awareness of the report's findings, ensure that people with a learning disability have opportunities to engage with LeDeR and empower people with a learning disability to advocate for change. The Staying Alive and Well group is also assisted by several stakeholder organisations, including the Estia Centre, Pathways Associates, the Foundation for People with Learning Disabilities, and the Baked Bean Theatre Company.
Treatable (avoidable) mortality/ death(s)	Deaths that could potentially be avoided through timely and effective healthcare, including early diagnosis, appropriate treatment, and prompt management of deterioration. For example, deaths from breast cancer detected too late despite screening availability, sepsis not treated promptly in hospital, or appendicitis with delayed surgery. Some causes of death are classified as both preventable and treatable under the OECD/Eurostat methodology and are therefore allocated equally between the two categories, which may result in counts including 0.5.
Underlying cause of death	The disease or injury that started the sequence of events leading to death, as recorded on the medical certificate of cause of death (MCCD).

Appendix 0.2: *Glossary of Abbreviations*

ATU	Assessment and Treatment Unit
BRC	Biomedical Research Centre
CBT	Cognitive Behavioural Therapy
CLDT	Community Learning Disability Team
CI	Confidence Interval
COPD	Chronic Obstructive Pulmonary Disease
COVID-19	Coronavirus Disease 2019
CPR	Cardiopulmonary Resuscitation
DHSC	Department of Health and Social Care
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
DVT	Deep Vein Thrombosis
GLM	Generalised Linear Model
GP	General Practitioner
ICD-10	International Classification of Diseases Version 10
ICB	Integrated Care Board
ICS	Integrated Care System
IMD	Index of Multiple Deprivation
IQR	Inter-Quartile Range
JCVI	Joint Committee on Vaccination and Immunisation
KCL	King's College London
LD	Learning Disability
LDLN	Learning Disability Liaison Nurse
LeDeR	Learning from Lives and Deaths – People with a Learning Disability and Autistic People
MDT	Multidisciplinary Team
MCA	Mental Capacity Act
MCCD	Medical Certificate of Cause of Death
MHA	Mental Health Act
NHS	National Health Service
NHSE	National Health Service England
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
OECD	Organisation for Economic Co-operation and Development
ONS	Office for National Statistics
OR	Odds Ratio
SCW	South Central and West Commissioning Support Unit
SD	Standard Deviation
SSRI	Selective Serotonin Reuptake Inhibitor
SUDEP	Sudden Unexpected Death in Epilepsy
WHO	World Health Organization

Appendix 0.3: *Research Methods*

This section describes the analytic approach used in the LeDeR 2024 report. Across the report, analyses drew on information collected at different stages of the LeDeR process. These included the notification, which is the first report of a death to LeDeR; the initial review, where reviewers gathered key information about the person's death and care; and the focused review, a more detailed review undertaken where there was greater potential for learning or in specific groups. Where appropriate, findings were compared with data from the general adult population in England to assess whether patterns differed. For this report, the general adult population refers to adults aged 20 years or above who died in England in 2024, unless otherwise stated. Data for this population were obtained from the Office for National Statistics.

Chapter 1 provides an overview of deaths of adults with a learning disability reported to LeDeR. Deaths of children and young people under the age of 18 are reported separately (see Learning from deaths: Children with a learning disability and autistic children aged 4 - 17 years). Notification data for deaths occurring between January 2021 and December 2024 were used to describe overall patterns, including the number of deaths over time, who notified the death, demographic characteristics, and age at death. Information gathered by reviewers through initial and focused reviews was used to examine circumstances of death, causes of death, avoidable mortality, and aspects of care such as DNACPR decisions, safeguarding, and whether the Mental Capacity Act was followed.

Chi-square tests were used to examine differences in categorical variables (e.g. presence of specific causes of death) across years, or between adults with a learning disability and the general population. Generalised linear models with a binomial distribution and an identity link were used to estimate year-on-year changes in risk differences over time in circumstances of death and avoidable mortality, and to test whether changes were statistically significant. Where supported by the data, linear changes over time were estimated; otherwise, estimates are presented relative to 2021. Differential changes over time by age group and sex were examined using GLMs with an interaction between year and either age group or sex. Kruskal-Wallis tests were used to compare differences in continuous variables (e.g. median age at death) by different mental health restriction status or contact with the criminal justice system in the 5 years before death. The same test was applied to two-group comparisons, where it is equivalent to the Wilcoxon rank-sum (Mann-Whitney U) test.

Chapters 2 and 3 followed a similar approach, focusing on subgroup comparisons. To ensure sufficient numbers for meaningful analysis, data from 2021 to 2024 were combined for most analyses. Chapter 2 compared adults with a mild or moderate learning disability with those with a severe or profound learning disability, with level of learning disability identified using information from both initial reviews and focused reviews. This differs from the 2023 report, which relied on a question introduced in the revised initial review form in January 2023. The current approach uses information from both review types and applies it retrospectively to deaths occurring between 2021 and 2024, resulting in substantially greater coverage and larger sample sizes than in previous analyses. Chapter 3 compared adults with a learning disability with Down syndrome and those without Down syndrome. To improve accuracy, Down syndrome status was identified using multiple sources, including coded fields, free-text review, and coded information from the Medical Certificate of Cause of Death (MCCD).

Across Chapters 2 and 3, analyses examined demographic characteristics, age at death, place of death, causes of death, avoidable mortality, long-term conditions, and quality of care. Results were summarised using counts and percentages, with chi-square tests used for group comparisons. Kaplan-Meier curves were used to compare the age at death between groups (for example, adults with versus without Down syndrome), with the log-rank test used to assess differences between curves. Median age at death is reported with 95% confidence intervals.

Cause of death analyses were primarily based on the underlying cause of death recorded on the MCCD. In Chapter 3, an alternative approach was also applied for adults with Down syndrome. Where Down syndrome itself was recorded as the underlying cause of death, this was reassigned to the next listed condition, or to a higher-level medical cause where appropriate. This approach allowed a more meaningful interpretation of the causes of death in this group.

Chapter 4 focused on autistic adults without a learning disability whose deaths were notified to LeDeR between June 2021 and December 2024. It described demographic characteristics, age at death, causes and place of death, physical and mental health conditions, use of mental health support, and indicators of care quality. Due to smaller sample sizes, findings are presented descriptively without formal statistical testing.

Structured qualitative analyses were undertaken across Chapters 1–4 using free-text comments from randomly selected focused reviews of deaths occurring between 2021 and 2024. A framework approach was applied, focusing on four predetermined areas: delays in care, gaps in care, problems with organisational systems, and diagnosis and treatment not meeting guidelines. Data were coded to identify recurring patterns, exploring what the issues were, where they occurred, and when in the care pathway they arose. Qualitative analyses included a sample of 280 focused reviews in Chapter 1, 160 focused reviews in Chapter 2, 163 focused reviews in Chapter 3 and 190 focused reviews in Chapter 4.

Statistical significance was assessed at the two-sided 5% level ($p<0.05$), and 95% confidence intervals are reported alongside point estimates where appropriate. Because multiple comparisons were made, findings with p-values should be interpreted with particular caution. Where relevant, the interpretation of specific findings is set out in the narrative text and in the accompanying table and figure legends. Results were summarised using counts and percentages for categorical variables, and medians with interquartile ranges for skewed continuous variables.

Appendix 0.4: *General Notes for Interpretation*

The protection of personal data

Values fewer than 5 (but greater than 0) are suppressed and shown as "*" to prevent identification of individuals; additional values may also be suppressed to avoid indirect identification across groups.

The use of hyperlinks

This report is primarily designed to be read as a digital document, with hyperlinks to relevant references and external sources highlighted throughout. A references page is also included.

The use of colour-coded tables

This report uses a colour code on specific tables. This is designed to highlight differences in the data presented, making it easier to interpret. The key for the colour coded tables can be found in Appendix 1.11.

The use of median and interquartile range

Median age at death is used throughout this report rather than mean (average) age, because the distribution of age at death in this population is skewed, that is, it is not evenly spread across the range of ages. In a skewed distribution, the mean can be disproportionately pulled towards extreme values at either end, making it a less reliable summary of where most deaths occur. The median, the middle value when all ages are ranked from lowest to highest, is less sensitive to these extremes and gives a more accurate picture of the typical age at death for this population. The interquartile range (IQR) shows how spread out the middle half of the values are, helping to give a clearer picture of variation.

Rounding of values

In all chapters, we have rounded to 1 decimal place for convenience. Where required, to provide more detailed figures when discussing statistics, for example *p*-values, we have used up to 3 decimal places.

Statistical significance

For statistical comparisons, *p*-values are reported to indicate the probability of obtaining the observed results, assuming that no true difference exists between groups. A *p*-value below 0.05 was considered to indicate statistical significance and that the observed finding is unlikely to be due to chance.

Presentation of data in tables

Unless otherwise stated, all data in tables are presented as counts and percentages to provide both the number of cases and their relative proportion.

Changes to data sources used in tables

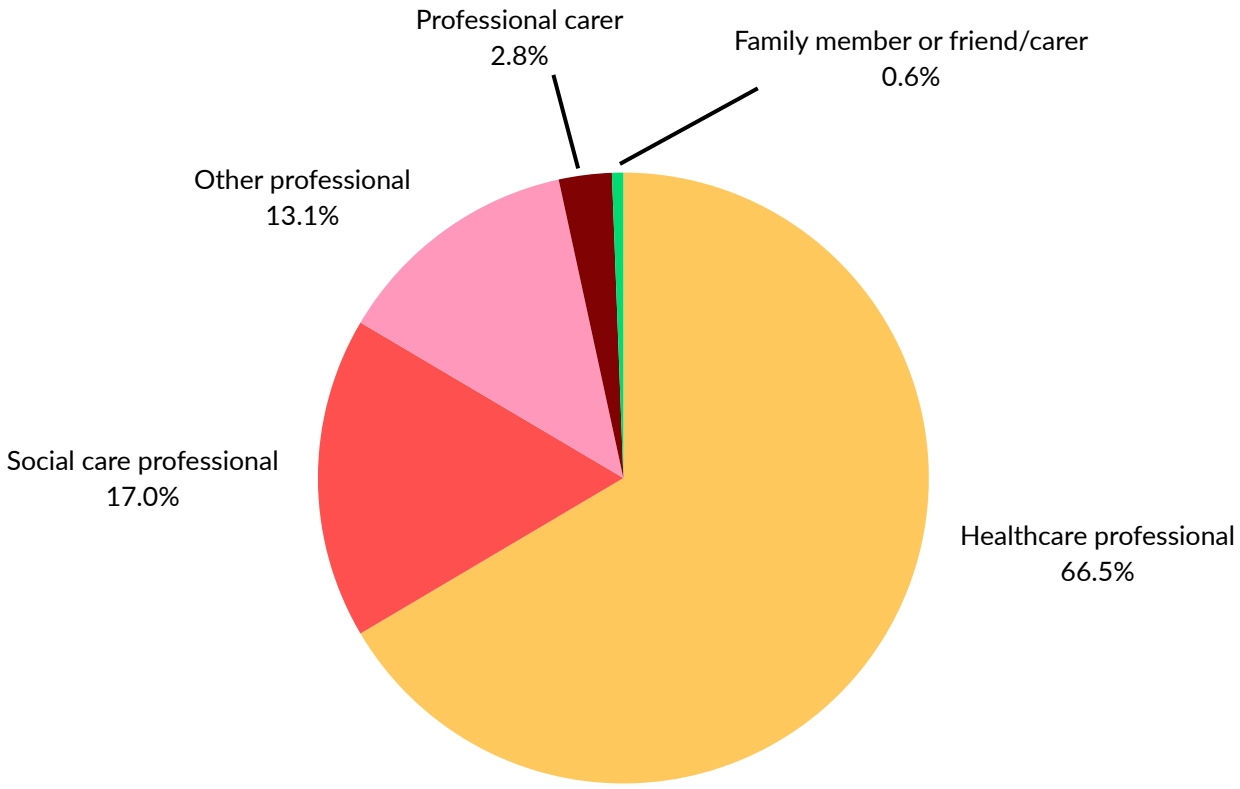
Some tables that were based on data from focused reviews in the 2023 report have been updated in this report using data gathered in initial reviews, as agreed with NHS England. This change was made to improve completeness and consistency across analyses. For comparison with the 2023 report, equivalent tables using focused review data are provided in Appendices 1.7, 1.16, 2.10, 2.16, 3.4, 3.14, 4.5.

Changes to the LeDeR process over time

King's College London (KCL) and the academic partnership began leading the LeDeR report from death reviews conducted in 2020, with the first report published by KCL in 2021. Prior to this, the University of Bristol team, who authored the reports from 2017 to 2019, were responsible for LeDeR data collection and data management. As a result, there are some differences between earlier and later datasets, including changes to review forms, available variables, data collection processes, and some data interpretations.

Chapter 1

Appendix 1.1: *Notifier relationship to adults with a learning disability who died in 2024 and whose deaths were notified to LeDeR*



Appendix 1.2: *Age group at death for adults with a learning disability who died between 2021 and 2024 compared with the general population using notifications*

	2021	2022	2023	2024	General adult population 2024	*p-value* (2024 vs Gen pop)
Age group						
18-24	128 (3.9%)	139 (4.3%)	126 (3.8%)	136 (4.0%)	1,236 (0.2%)	
25-49	577 (17.8%)	580 (18.0%)	603 (17.9%)	612 (18.0%)	20,610 (3.9%)	
50-64	1,177 (36.2%)	1,152 (35.8%)	1,226 (36.5%)	1,173 (34.6%)	56,644 (10.7%)	**<0.001**
65+	1,367 (42.1%)	1,343 (41.8%)	1,405 (41.8%)	1,474 (43.4%)	449,257 (85.1%)	
Total	3,249 (100.0%)	3,214 (100.0%)	3,360 (100.0%)	3,395 (100.0%)	527,747 (100.0%)	

Appendix 1.3: *Full harmonised list of ethnic groups used by LeDeR*

Broad ethnic group	Harmonised ethnic group*
Asian or Asian British	Indian
	Pakistani
	Bangladeshi
	Chinese
	Any other Asian background
Black, African, Caribbean or Black British	African
	Caribbean
	Any other Black, African or Caribbean background
Mixed or multiple ethnic groups	White and Black Caribbean
	White and Black African
	White and Asian
	Any other Mixed or Multiple ethnic background
Other ethnic groups	Arab
	Any other ethnic group
They preferred not to say	They preferred not to say (Initial Review only)
White	British
	Irish
	Gypsy or Irish Traveller
	Any White background

*For full details on the harmonised list of ethnic groups see: Ethnic group, national identity and religion - Office for National Statistics

Appendix 1.4: *Demographics of adults with a learning disability who died in 2024 using initial reviews.*

Demographic	2024	General adult population 2024	*p-value*
Sex registered at birth			
Female	1,155 (42.6%)	259,354 (49.1%)	**<0.001**
Male	1,489 (54.9%)	268,393 (50.9%)	
Not known	69 (2.5%)	0 (0.0%)	
Total	2,713 (100.0%)	527,747 (100.0%)	
Ethnic group			
Asian or Asian British	101 (3.7%)	±	-
Black African, Caribbean, or Black British	50 (1.8%)	±	-
Mixed ethnic group	14 (0.5%)	±	-
Other ethnic group	11 (0.4%)	±	-
Preferred not to say	83 (3.1%)	±	-
White	2,454 (90.5%)	±	-
Total	2,713 (100.0%)	±	-
Region			
London	273 (10.1%)	49,962 (9.5%)	**<0.001**
South West	279 (10.3%)	60,977 (11.6%)	
South East	387 (14.3%)	86,885 (16.5%)	
Midlands	568 (20.9%)	107,829 (20.4%)	
East of England	315 (11.6%)	60,368 (11.4%)	
North West	361 (13.3%)	76,170 (14.4%)	
North East and Yorkshire	530 (19.5%)	85,556 (16.2%)	
Total	2,713 (100.0%)	527,747 (100.0%)	
Index of multiple deprivation decile			
1 (most deprived)	365 (13.5%)	54,506 (10.3%)	**<0.001**
2	357 (13.2%)	51,368 (9.7%)	
3	307 (11.3%)	50,258 (9.5%)	
4	308 (11.4%)	52,840 (10.0%)	
5	299 (11.0%)	53,741 (10.2%)	
6	263 (9.7%)	55,054 (10.4%)	
7	268 (9.9%)	54,778 (10.4%)	
8	242 (8.9%)	53,795 (10.2%)	
9	190 (7.0%)	52,760 (10.0%)	
10 (least deprived)	*	*	
Not Known	*	*	
Total	2,713 (100.0%)	527,747 (100.0%)	

* Fewer than five cases
± Data not available

Appendix 1.5: *Sexual orientation, marital status, children, and employment by year for adults with a learning disability who died between 2021 and 2024, using initial reviews.*

	2021	2022	2023	2024
Sexual orientation**				
Heterosexual or straight	47 (1.7%)	622 (19.7%)	976 (31.8%)	604 (22.3%)
Gay or Lesbian	0 (0.0%)	*	*	5 (0.2%)
Bisexual	0 (0.0%)	*	*	*
Other	0 (0.0%)	*	12 (0.4%)	*
Not known	2,702 (98.3%)	2,524 (80.0%)	2,072 (67.5%)	2,102 (77.5%)
Total	2,749 (100.0%)	3,154 (100.0%)	3,071 (100.0%)	2,713 (100.0%)
Marital status				
Single	2,073 (75.4%)	2,667 (84.6%)	2,643 (86.1%)	2,228 (82.1%)
Married or civil partnership	54 (2.0%)	81 (2.6%)	72 (2.3%)	64 (2.4%)
Separated	8 (0.3%)	11 (0.3%)	10 (0.3%)	13 (0.5%)
Divorced	29 (1.1%)	34 (1.1%)	17 (0.6%)	23 (0.8%)
Widowed	37 (1.3%)	45 (1.4%)	39 (1.3%)	28 (1.0%)
Not known	548 (19.9%)	316 (10.0%)	290 (9.4%)	357 (13.2%)
Total	2,749 (100.0%)	3,154 (100.0%)	3,071 (100.0%)	2,713 (100.0%)
Children				
Yes	87 (3.2%)	133 (4.2%)	118 (3.8%)	86 (3.2%)
No	2,068 (75.2%)	2,491 (79.0%)	2,407 (78.4%)	1,940 (71.5%)
Not known	594 (21.6%)	530 (16.8%)	546 (17.8%)	687 (25.3%)
Total	2,749 (100.0%)	3,154 (100.0%)	3,071 (100.0%)	2,713 (100.0%)
Employment				
Employed (paid)	19 (0.7%)	19 (0.6%)	18 (0.6%)	11 (0.4%)
Employed (voluntary)	22 (0.8%)	29 (0.9%)	27 (0.9%)	14 (0.5%)
No	2,221 (80.8%)	2,654 (84.1%)	2,584 (84.1%)	2,156 (79.5%)
I don't know	487 (17.7%)	452 (14.3%)	442 (14.4%)	532 (19.6%)
Total	2,749 (100.0%)	3,154 (100.0%)	3,071 (100.0%)	2,713 (100.0%)

*Fewer than five

**Sexuality was not directly asked until 2022. For the row "Not known," reviewers had the option of inputting either "asked and does not know or is not sure" or "person asked but declined to provide a response." For this report, both options have been combined with blank responses.

Appendix 1.6: *Circumstances of death of adults with a learning disability who died between 2021 and 2024, compared with the general population using initial reviews.*

Circumstances at death	2021	2022	2023	2024	*p-value (2021-2024)*	General adult population 2024**	*p-value (2024 vs Gen Pop)*
DNACPR decision at death							
Yes	1,984 (72.2%)	2,254 (71.5%)	2,281 (74.3%)	2,099 (77.4%)	<0.001	±	-
No	*	900 (28.5%)	790 (25.7%)	614 (22.6%)			
Not known	*	0 (0.0%)	0 (0.0%)	0 (0.0%)			
Total	2,749 (100.0%)	3,154 (100.0%)	3,071 (100.0%)	2,713 (100.0%)			
(if yes to above) Was the DNACPR documentation correctly completed and followed?							
Completed and followed	1,201 (60.5%)	1,384 (61.4%)	1,389 (60.9%)	1,315 (62.6%)	0.043***	±	-
Completed but not followed correctly	21 (1.1%)	27 (1.2%)	13 (0.6%)	23 (1.1%)			
Incorrectly completed and followed	126 (6.4%)	170 (7.5%)	183 (8.0%)	139 (6.6%)			
Neither completed nor followed correctly	13 (0.7%)	18 (0.8%)	8 (0.4%)	6 (0.3%)			
Not known	623 (31.4%)	655 (29.1%)	688 (30.2%)	616 (29.3%)			
Total	1,984 (100.0%)	2,254 (100.0%)	2,281 (100.0%)	2,099 (100.0%)			
Reported to a coroner?							
Yes	707 (25.7%)	847 (26.9%)	859 (28.0%)	665 (24.5%)	<0.001	174,878 (30.8%)	<0.001
No	550 (20.0%)	544 (17.2%)	537 (17.5%)	458 (16.9%)		393,735 (69.2%)	
Not known	1,492 (54.3%)	1,763 (55.9%)	1,675 (54.5%)	1,590 (58.6%)		0 (0.0%)	
Total	2,749 (100.0%)	3,154 (100.0%)	3,071 (100.0%)	2,713 (100.0%)		568,613 (100.0%)	
Was there a police investigation?							
Yes	169 (6.1%)	256 (8.1%)	288 (9.4%)	221 (8.1%)	<0.001	±	-
No	1,088 (39.6%)	1,135 (36.0%)	1,108 (36.1%)	902 (33.2%)		±	-
Not known	1,492 (54.3%)	1,763 (55.9%)	1,675 (54.5%)	1,590 (58.6%)		±	-
Total	2,749 (100.0%)	3,154 (100.0%)	3,071 (100.0%)	2,713 (100.0%)		±	-
Was there a safeguarding concern?							
Yes	235 (8.5%)	226 (7.2%)	264 (8.6%)	137 (5.0%)	<0.001	±	-
No	1,022 (37.2%)	1,165 (36.9%)	1,132 (36.9%)	986 (36.3%)		±	-
Not known	1,492 (54.3%)	1,763 (55.9%)	1,675 (54.5%)	1,590 (58.6%)		±	-
Total	2,749 (100.0%)	3,154 (100.0%)	3,071 (100.0%)	2,713 (100.0%)		±	-

* Fewer than five cases
± Data not available
**Provisional data, includes deaths of all ages in England and Wales.
***Two p-values are reported for DNACPR documentation quality. The p-value shown in the table (p=0.043) is from a chi-square test (4×5) comparing the distribution across the five recorded documentation outcomes. The p-value is statistically insignificant (p=0.52) when we performed a separate chi-square test (4x2) comparing the proportion of DNACPR decisions recorded as 'completed and followed correctly' against all other responses combined.

Appendix 1.7: *Circumstances of death of adults with a learning disability who died between 2021 and 2024, using focused reviews.*

Circumstances at death	2021	2022	2023	2024	*p-value (2021-2024)*
Death reported to a coroner?**					
Yes	255 (40.5%)	394 (41.6%)	351 (40.6%)	263 (36.3%)	0.289
No	360 (57.2%)	537 (56.7%)	496 (57.4%)	451 (62.3%)	
Not known	14 (2.2%)	16 (1.7%)	17 (2.0%)	10 (1.4%)	
Total	629 (100.0%)	947 (100.0%)	864 (100.0%)	724 (100.0%)	
Was there a police investigation?**					
Yes	31 (4.9%)	38 (4.0%)	25 (2.9%)	12 (1.7%)	**<0.001**
No	598 (95.1%)	909 (96.0%)	839 (97.1%)	712 (98.3%)	
Total	629 (100.0%)	947 (100.0%)	864 (100.0%)	724 (100.0%)	
Safeguarding concerns**					
Yes	107 (17.0%)	99 (10.5%)	76 (8.8%)	50 (6.9%)	**<0.001**
No	522 (83.0%)	848 (89.5%)	788 (91.2%)	674 (93.1%)	
Total	629 (100.0%)	947 (100.0%)	864 (100.0%)	724 (100.0%)	

* Fewer than five cases

**Sections are based on focused reviews and are included to maintain comparability with the LeDeR 2023 annual report.

Appendix 1.8: *Circumstances prior to death for adults with a learning disability who died between 2021 and 2024, using initial reviews.*

Circumstances prior to death	2021-2024	Median age at death (IQR)	*p-value*
Place of residence at death			
Family home	846 (26.7%)	39.7 (25.7-54.9)	**<0.001**
Home of a friend or relative	28 (0.9%)	59.3 (42.3-67.7)	
Supported living tenancy	711 (22.5%)	59.7 (50.1-67.5)	
Owned	31 (1.0%)	61.2 (45.3-69.0)	
Rented	205 (6.5%)	60.3 (50.5-69.6)	
Residential nursing home	1,214 (38.4%)	62.1 (54.3-69.8)	
Other	129 (4.1%)	57.5 (40.3-69.5)	
Total	3,164 (100.0%)	57.4 (42.6-66.5)	
Was the person who died placed out-of-area?			
Yes	267 (8.4%)	58.6 (45.9-67.5)	**0.016**
No	2,738 (86.5%)	57.2 (42.0-66.3)	
Not known	159 (5.0%)	60.3 (51.6-68.4)	
Total	3,164 (100.0%)	57.4 (42.6-66.5)	
Contact with the criminal justice system in the 5 years before death			
Yes	81 (0.7%)	43.1 (34.4-54.6)	**<0.001**
No	8,857 (75.8%)	62.7 (53.8-72.3)	
Don't know/Not known	2,749 (23.5%)	63.0 (53.8-72.4)	
Total	11,687 (100.0%)	62.7 (52.8-72.3)	
Mental health restrictions in the 5 years before death			
Yes	438 (3.7%)	62.1 (54.7-70.7)	**<0.001**
No	8,492 (72.7%)	62.5 (52.2-72.1)	
Don't know/Not known	2,757 (23.6%)	63.5 (54.2-73.1)	
Total	11,687 (100.0%)	62.7 (52.8-72.3)	

Appendix 1.9: *Full description and codes for ICD-10 Chapters*

Chapter	Code Range	Description
I	A00-B99	Certain infectious and parasitic diseases
II	C00-D49	Neoplasms
III	D50-D89	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism
IV	E00-E89	Endocrine, nutritional and metabolic diseases
V	F01-F99	Mental, Behavioural and Neurodevelopmental disorders
VI	G00-G99	Diseases of the nervous system
VII	H00-H59	Diseases of the eye and adnexa
VIII	H60-H95	Diseases of the ear and mastoid process
IX	I00-I99	Diseases of the circulatory system
X	J00-J99	Diseases of the respiratory system
XI	K00-K95	Diseases of the digestive system
XII	L00-L99	Diseases of the skin and subcutaneous tissue
XIII	M00-M99	Diseases of the musculoskeletal system and connective tissue
XIV	N00-N99	Diseases of the genitourinary system
XV	O00-O99	Pregnancy, childbirth and the puerperium
XVI	P00-P96	Certain conditions originating in the perinatal period
XVII	Q00-Q99	Congenital malformations, deformations and chromosomal abnormalities
XVIII	R00-R99	Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified
XIX	S00-T88	Injury, poisoning and certain other consequences of external causes
XX	V00-Y99	External causes of morbidity and mortality
XXI	Z00-Z99	Factors influencing health status and contact with health services
XXII	U00-U85	Codes for special purposes (including provisional assignment of new diseases)

Appendix 1.10: *Most common causes of death of adults with a learning disability who died between 2021 and 2024, (by ICD-10 chapter) compared with the general population using initial reviews.*

	2021	2022	2023	2024	*p-value (2021-2024)*	General adult population 2024	*p-value (2024 vs Gen pop)*
Diseases of the respiratory system	356 (13.0%)	483 (15.4%)	483 (15.9%)	447 (16.6%)		64,108 (12.1%)	
Diseases of the circulatory system	419 (15.4%)	504 (16.1%)	519 (17.0%)	436 (16.2%)		126,111 (23.9%)	
Neoplasms	358 (13.1%)	436 (13.9%)	465 (15.3%)	417 (15.5%)		142,833 (27.1%)	
Diseases of the nervous system	333 (12.2%)	440 (14.0%)	413 (13.6%)	363 (13.5%)		41,942 (7.9%)	
Congenital malformations, deformations and chromosomal abnormalities	312 (11.4%)	388 (12.4%)	387 (12.7%)	359 (13.3%)		1,169 (0.2%)	
Diseases of the digestive system	177 (6.5%)	233 (7.4%)	198 (6.5%)	194 (7.2%)		28,228 (5.3%)	
Mental and behavioural disorders*	124 (4.5%)	109 (3.5%)	117 (3.8%)	107 (4.0%)	**<0.001**	40,850 (7.7%)	**<0.001**
Endocrine, nutritional and metabolic diseases	55 (2.0%)	74 (2.4%)	71 (2.3%)	81 (3.0%)		9,958 (1.9%)	
Diseases of the genitourinary system	67 (2.5%)	75 (2.4%)	79 (2.6%)	68 (2.5%)		8,359 (1.6%)	
External causes of morbidity and mortality**	88 (3.2%)	102 (3.3%)	99 (3.3%)	65 (2.4%)		24,646 (4.7%)	
Provisional assignment of new diseases***	328 (12.0%)	156 (5.0%)	52 (1.7%)	30 (1.1%)		6,140 (1.2%)	
Total known causes of mortality******	2,728 (100.0%)	3,138 (100.0%)	3,046 (100.0%)	2,692 (100.0%)		527,747 (100.0%)	

*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.
**External causes of morbidity and mortality (ICD-10 Chapter XX) include deaths resulting from injuries or other external events, such as accidents, exposure to harmful substances, or intentional self-harm (suicide).
***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).
**** Only the most common causes of death are shown in this table. Less common causes of death are not presented individually, and therefore the total does not equal the total number of deaths.

Appendix 1.11: *Most common underlying ICD-10 code causes of death for the 10 most common ICD-10 chapter causes of death of adults with a learning disability who died between 2021 and 2024 using initial reviews.*

	2021	2022	2023	2024
Diseases of the respiratory system	356 (13.0%)	483 (15.4%)	483 (15.9%)	447 (16.6%)
Pneumonia, unspecified	98 (3.6%)	137 (4.4%)	154 (5.1%)	158 (5.9%)
Unspecified acute lower respiratory infection	34 (1.2%)	46 (1.5%)	56 (1.8%)	51 (1.9%)
Bronchopneumonia, unspecified	67 (2.5%)	76 (2.4%)	77 (2.5%)	47 (1.7%)
Diseases of the circulatory system	419 (15.4%)	504 (16.1%)	519 (17.0%)	436 (16.2%)
Acute myocardial infarction, unspecified	50 (1.8%)	57 (1.8%)	63 (2.1%)	57 (2.1%)
Atherosclerotic heart disease	49 (1.8%)	61 (1.9%)	47 (1.5%)	47 (1.7%)
Stroke, not specified as haemorrhage or infarction	46 (1.7%)	54 (1.7%)	47 (1.5%)	45 (1.7%)
Neoplasms	358 (13.1%)	436 (13.9%)	465 (15.3%)	417 (15.5%)
Breast, unspecified	26 (1.0%)	35 (1.1%)	44 (1.4%)	35 (1.3%)
Malignant neoplasm, primary site unknown, so stated	17 (0.6%)	25 (0.8%)	27 (0.9%)	31 (1.2%)
Bronchus or lung, unspecified	27 (1.0%)	33 (1.1%)	25 (0.8%)	26 (1.0%)
Diseases of the nervous system	333 (12.2%)	440 (14.0%)	413 (13.6%)	363 (13.5%)
Cerebral palsy, unspecified**	115 (4.2%)	170 (5.4%)	152 (5.0%)	108 (4.0%)
Epilepsy, unspecified	74 (2.7%)	99 (3.2%)	92 (3.0%)	89 (3.3%)
Parkinson disease	18 (0.7%)	23 (0.7%)	18 (0.6%)	17 (0.6%)
Congenital malformations, deformations and chromosomal abnormalities	312 (11.4%)	388 (12.4%)	387 (12.7%)	359 (13.3%)
Down syndrome, unspecified**	229 (8.4%)	284 (9.1%)	270 (8.9%)	269 (10.0%)
Congenital malformation of heart, unspecified	9 (0.3%)	10 (0.3%)	8 (0.3%)	11 (0.4%)
Microcephaly	9 (0.3%)	*	11 (0.4%)	7 (0.3%)
Diseases of the digestive system	177 (6.5%)	233 (7.4%)	198 (6.5%)	194 (7.2%)
Other and unspecified intestinal obstruction	20 (0.7%)	22 (0.7%)	24 (0.8%)	27 (1.0%)
Volvulus	34 (1.2%)	21 (0.7%)	23 (0.8%)	27 (1.0%)
Gastrointestinal haemorrhage, unspecified	8 (0.3%)	15 (0.5%)	11 (0.4%)	12 (0.4%)
Mental and behavioural disorders* **	124 (4.5%)	109 (3.5%)	117 (3.8%)	107 (4.0%)
Unspecified dementia	62 (2.3%)	64 (2.0%)	69 (2.3%)	66 (2.5%)
Vascular dementia, unspecified	14 (0.5%)	12 (0.4%)	21 (0.7%)	17 (0.6%)
Developmental disorder of scholastic skills, unspecified	35 (1.3%)	14 (0.4%)	16 (0.5%)	9 (0.3%)
Endocrine, nutritional and metabolic diseases	55 (2.0%)	74 (2.4%)	71 (2.3%)	81 (3.0%)
Obesity, unspecified	*	12 (0.4%)	*	9 (0.3%)
Type 2 diabetes mellitus without complications	*	5 (0.2%)	*	*
Other obesity	*	*	*	*
Diseases of the genitourinary system	67 (2.5%)	75 (2.4%)	79 (2.6%)	68 (2.5%)
Urinary tract infection, site not specified	37 (1.4%)	43 (1.4%)	35 (1.1%)	37 (1.4%)
Calculus of kidney	8 (0.3%)	*	8 (0.3%)	*
Obstructive and reflux uropathy, unspecified	*	0 (0.0%)	*	*
External causes of morbidity and mortality**	88 (3.2%)	102 (3.3%)	99 (3.3%)	65 (2.4%)
Unspecified fall	19 (0.7%)	21 (0.7%)	24 (0.8%)	12 (0.4%)
Exposure to unspecified factor causing fracture	*	6 (0.2%)	*	8 (0.3%)
Inhalation and ingestion of food causing obstruction of respiratory tract	20 (0.7%)	14 (0.4%)	18 (0.6%)	6 (0.2%)

Total known causes of mortality***	2,728 (100.0%)	3,138 (100.0%)	3,046 (100.0%)	2,692 (100.0%)

* Fewer than five cases
**Although Down syndrome and cerebral palsy should not be listed as the sole cause of death on the MCCD, 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).
***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.
****External causes of morbidity and mortality (ICD-10 Chapter XX) include deaths resulting from injuries or other external events, such as accidents, exposure to harmful substances, or intentional self-harm.
***** Only the most common causes of death are shown in this table. Less common causes of death are not presented individually and therefore the total does not equal the total number of known causes of death.

Appendix 1.12: *Colour coding used in Chapter 1, Table 1.4*

U071: COVID-19, virus identified
Q909: Down syndrome, unspecified
G809: Cerebral palsy, unspecified
G409: Epilepsy, unspecified
J189: Pneumonia, unspecified
J180: Bronchopneumonia, unspecified
J22: Unspecified acute lower respiratory infection
F03: Unspecified dementia
I21.9: Acute myocardial infarction
I25.1: Atherosclerotic heart disease
I25.9: Chronic ischaemic heart disease, unspecified
I64: Stroke, not specified as haemorrhage or infarction

Appendix 1.13: *Avoidable mortality of adults with a learning disability who died between 2021 and 2024, compared with the general population using initial reviews.*

Avoidable mortality	2021	2022	2023	2024	*p-value* (2021-2024)	2024 (% of all deaths with known causes)	General adult population 2024	*p-value* (2024 vs Gen pop)	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%)	**<0.001**	1,049 (39.0%) (37.1-40.8%)	111,614 (21.1%) (21.0-21.3%)	**<0.001**	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%)	**<0.001**	376.5 (14.0%) (12.7-15.4%)	71,426.5 (13.5%) (13.4-13.6%)	0.495	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%)	0.13	672.5 (25.0%) (23.4-26.7%)	40,187.5 (7.6%) (7.5-7.7%)	**<0.001**	40,187.5 (7.6%) (7.5-7.7%)
Total known causes of mortality	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%)	0.52	37 (1.4%)	891 (72.1%)	<0.001	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%)	<0.001	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%)	<0.001	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%)	<0.001	54,136 (10.3%)
Avoidable mortality by sex									
Female	541 (45.9%)	558 (40.4%)	485 (38.6%)	442 (38.5%)	0.19	442 (16.4%)	43,293 (16.7%)	<0.001	43,293 (8.2%)
Male	712 (46.8%)	779 (45.7%)	744 (42.9%)	578 (39.2%)		578 (21.5%)	67,750 (25.2%)	<0.001	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 columns show the percentage % of all 2024 deaths with all known causes of deaths in that population (2024 denominator 2,692; general adult population 527,747).

Appendix 1.14: *Most common avoidable causes of death of adults with a learning disability who died between 2021 and 2024 (by OECD classification), compared with the general population using initial reviews.*

Avoidable causes of death (by OECD classification)*		2021	2022	2023	2024	General adult population 2024	*p-value* (2024 vs Gen Pop)
Pneumonia, not elsewhere classified or organism unspecified		133 (10.5%)	168 (12.3%)	169 (13.4%)	142 (13.5%)	3,264 (2.9%)	**<0.001**
Ischaemic heart disease		114 (9.0%)	142 (10.4%)	125 (9.9%)	104 (9.9%)	19,386 (17.4%)	**<0.001**
Epilepsy		84 (6.7%)	103 (7.6%)	101 (8.0%)	99 (9.4%)	551 (0.5%)	**<0.001**
Avoidable mortality by sex**							
Female	**Pneumonia, not elsewhere classified or organism unspecified**	59 (10.9%)	67 (12.0%)	56 (11.5%)	58 (13.1%)	1,286 (3.0%)	**<0.001**
	Epilepsy	37 (6.8%)	45 (8.1%)	41 (8.5%)	38 (8.6%)	211 (0.5%)	**<0.001**
	Ischaemic heart disease	34 (6.3%)	45 (8.1%)	32 (6.6%)	34 (7.7%)	4,573 (10.6%)	**0.019**
Male	**Pneumonia, not elsewhere classified or organism unspecified**	74 (10.4%)	97 (12.5%)	108 (14.5%)	80 (13.8%)	1,978 (2.9%)	**<0.001**
	Ischaemic heart disease	79 (11.1%)	94 (12.1%)	88 (11.8%)	64 (11.1%)	14,813 (21.9%)	**<0.001**
	Epilepsy	44 (6.2%)	57 (7.3%)	57 (7.7%)	57 (9.9%)	340 (0.5%)	**<0.001**

*Data are presented as numbers (percentages of adults in each group of deaths with avoidable causes).

** Sex specific analyses exclude deaths where sex was not known.

Appendix 1.15: *Quality of care of adults with a learning disability who died between 2021 and 2024, using initial reviews.*

Quality of care	2021	2022	2023	2024	*p-value (2021-2024)*
Use of the Mental Capacity Act					
Correctly followed	1,793 (65.2%)	2,077 (65.9%)	2,067 (67.3%)	1,808 (66.6%)	**<0.001**
Not correctly followed	202 (7.3%)	230 (7.3%)	205 (6.7%)	129 (4.8%)	
Not known	754 (27.4%)	847 (26.9%)	799 (26.0%)	776 (28.6%)	
Total	2,749 (100.0%)	3,154 (100.0%)	3,071 (100.0%)	2,713 (100.0%)	
Good practice identified					
Yes	1,731 (63.0%)	2,272 (72.0%)	2,268 (73.9%)	1,662 (61.3%)	**<0.001**
No	1,018 (37.0%)	882 (28.0%)	803 (26.1%)	1,051 (38.7%)	
Total	2,749 (100.0%)	3,154 (100.0%)	3,071 (100.0%)	2,713 (100.0%)	
Concerns identified					
Yes	854 (31.1%)	322 (10.2%)	295 (9.6%)	193 (7.1%)	**<0.001**
No concerns	1,065 (38.7%)	1,960 (62.1%)	1,967 (64.1%)	1,826 (67.3%)	
Not known	830 (30.2%)	872 (27.6%)	809 (26.3%)	694 (25.6%)	
Total	2,749 (100.0%)	3,154 (100.0%)	3,071 (100.0%)	2,713 (100.0%)	

Appendix 1.16: *Quality of care of adults with a learning disability who died between 2021 and 2024, using focused reviews.*

Quality of care	2021	2022	2023	2024	*p-value (2021-2024)*
Concerns identified*					
Yes	258 (41.0%)	308 (32.5%)	258 (29.9%)	184 (25.4%)	**<0.001**
No	291 (46.3%)	625 (66.0%)	595 (68.9%)	532 (73.5%)	
Not known	80 (12.7%)	14 (1.5%)	11 (1.3%)	8 (1.1%)	
Total	629 (100.0%)	947 (100.0%)	864 (100.0%)	724 (100.0%)	
Care package met the needs of the person					
Yes	464 (73.8%)	728 (76.9%)	643 (74.4%)	574 (79.3%)	0.056
No	165 (26.2%)	219 (23.1%)	221 (25.6%)	150 (20.7%)	
Total	629 (100.0%)	947 (100.0%)	864 (100.0%)	724 (100.0%)	
Reasonable adjustments made					
All reasonable adjustments provided	415 (66.0%)	704 (74.3%)	635 (73.5%)	563 (77.8%)	**<0.001**
Reasonable adjustments should have been provided but were not	214 (34.0%)	243 (25.7%)	229 (26.5%)	161 (22.2%)	
Total	629 (100.0%)	947 (100.0%)	864 (100.0%)	724 (100.0%)	

*Sections are based on focused reviews and are included to maintain comparability with the LeDeR 2023 annual report.

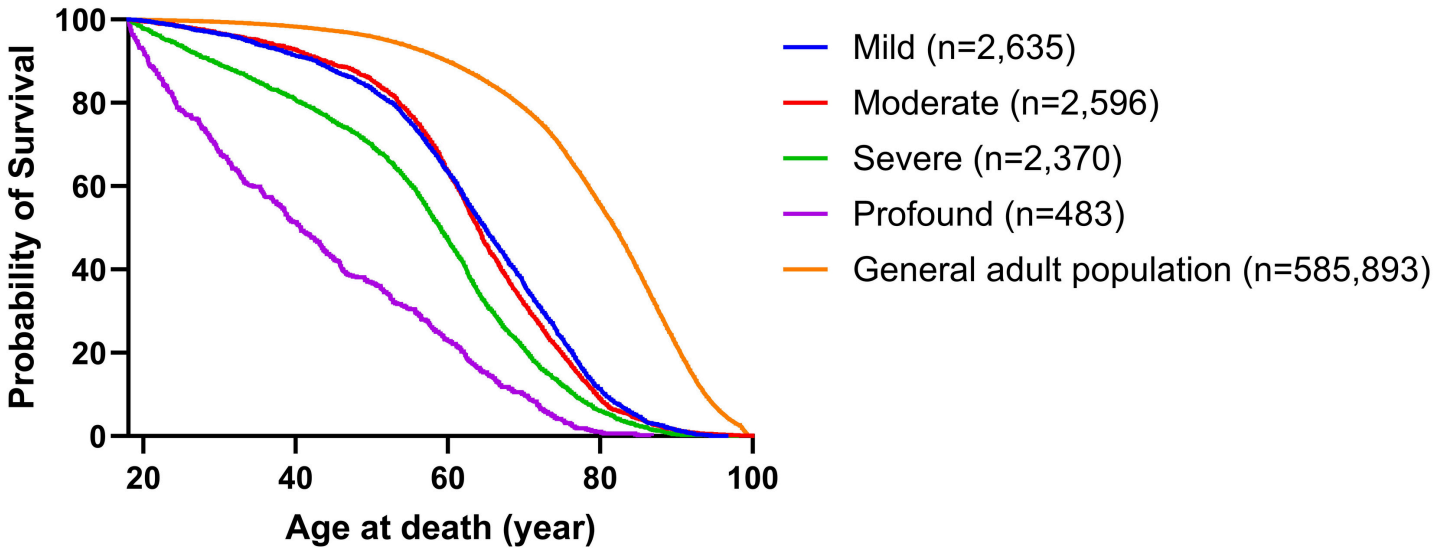
Chapter 2

Appendix 2.1: *Annual deaths of adults with a learning disability who died between 2021 and 2024, by detailed level of learning disability using initial reviews.*

Level of learning disability*	2021	2022	2023	2024	Total
Mild	188 (27.7%)	633 (32.6%)	976 (33.7%)	838 (32.6%)	2,635 (32.6%)
Moderate	219 (32.3%)	619 (31.9%)	950 (32.8%)	808 (31.5%)	2,596 (32.1%)
Severe	220 (32.4%)	562 (28.9%)	817 (28.2%)	771 (30.0%)	2,370 (29.3%)
Profound	51 (7.5%)	129 (6.6%)	151 (5.2%)	152 (5.9%)	483 (6.0%)
Total	678 (100.0%)	1,943 (100.0%)	2,894 (100.0%)	2,569 (100.0%)	8,084 (100.0%)

*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.

Appendix 2.2: *Survival curves of adults with a learning disability who died between 2021 and 2024 by level of learning disability*



The median age at death declined as the level of learning disability increased. Adults with a mild learning disability had a median age at death of 64.9 years (95% CI: 64.1–65.6 years), while those with a moderate learning disability had a similar median age of 63.9 years (95% CI: 63.4–64.5 years). This decreased among adults with a severe learning disability, whose median age at death was 59.0 years (95% CI: 58.2–59.7 years), and was lowest among those with a profound learning disability at 40.7 years (95% CI: 38.5–43.3 years). All groups had considerably lower median ages at death compared with the general adult population in England and Wales in 2022 (81.9 years, 95% CI: 81.9–82.0 years; $p<0.001$).

Appendix 2.3: *Most common causes of death (by ICD-10 chapter) of adults with a learning disability who died between 2021 and 2024, by detailed level of learning disability, using initial reviews.*

Causes of death (ICD-10 chapter)	Mild	Moderate	Severe	Profound
Diseases of the circulatory system	550 (21.0%)	405 (15.7%)	264 (11.2%)	21 (4.4%)
Neoplasms	526 (20.1%)	347 (13.5%)	258 (11.0%)	35 (7.4%)
Diseases of the respiratory system	428 (16.4%)	389 (15.1%)	398 (16.9%)	73 (15.4%)
Diseases of the nervous system	208 (8.0%)	300 (11.6%)	458 (19.5%)	171 (36.2%)
Diseases of the digestive system	192 (7.3%)	179 (6.9%)	161 (6.8%)	40 (8.5%)
Congenital malformations	134 (5.1%)	449 (17.4%)	362 (15.4%)	54 (11.4%)
External causes	118 (4.5%)	81 (3.1%)	64 (2.7%)	9 (1.9%)
Endocrine and metabolic diseases	96 (3.7%)	49 (1.9%)	50 (2.1%)	15 (3.2%)
Mental and behavioural disorders	82 (3.1%)	113 (4.4%)	91 (3.9%)	10 (2.1%)
Diseases of the genitourinary system	76 (2.9%)	66 (2.6%)	53 (2.3%)	7 (1.5%)
Total known causes of mortality*	2,613 (100.0%)	2,576 (100.0%)	2,354 (100.0%)	473 (100.0%)

*Only the most common causes of death are shown in this table. Less common causes of death are not presented individually and therefore the total does not equal the total number of known causes of death.

Appendix 2.4: *Avoidable mortality of adults with a learning disability who died between 2021 and 2024, by detailed level of learning disability, using initial reviews.*

Avoidable mortality	Mild	Moderate	Severe	Profound
Avoidable (preventable and treatable) (95% CI)	1,245 (47.6%) (45.7-49.6%)	1,001 (38.9%) (37.0-40.8%)	975 (41.4%) (39.4-43.4%)	170 (35.9%) (31.6-40.4%)
Preventable (95% CI)	567 (21.7%) (20.1-23.3%)	395.5 (15.4%) (14.0-16.8%)	323 (13.7%) (12.4-15.2%)	54.5 (11.5%) (8.9-14.9%)
Treatable (95% CI)	678 (25.9%) (24.3-27.7%)	605.5 (23.5%) (21.9-25.2%)	652 (27.7%) (25.9-29.5%)	115.5 (24.4%) (20.7-28.7%)
Total known causes of mortality	2,613 (100.0%)	2,576 (100.0%)	2,354 (100.0%)	473 (100.0%)

Appendix 2.5: *Most common avoidable causes of mortality of adults with a learning disability who died between 2021 and 2024 (by OECD classification), by detailed level of learning disability, using initial reviews.*

Avoidable causes of mortality (by OECD classification)	Mild	Moderate	Severe	Profound
Ischaemic heart diseases	144 (11.6%)	100 (10.0%)	55 (5.6%)	5 (2.9%)
Pneumonia, not elsewhere classified	122 (9.8%)	133 (13.3%)	167 (17.1%)	23 (13.5%)
Cerebrovascular diseases	85 (6.8%)	68 (6.8%)	83 (8.5%)	8 (4.7%)
Chronic lower respiratory diseases	77 (6.2%)	25 (2.5%)	*	*
Colorectal cancer	66 (5.3%)	39 (3.9%)	35 (3.6%)	5 (2.9%)
Accidental injuries	59 (4.7%)	51 (5.1%)	*	*
Epilepsy	56 (4.5%)	87 (8.7%)	131 (13.4%)	23 (13.5%)
COVID-19	52 (4.2%)	61 (6.1%)	62 (6.4%)	14 (8.2%)
Venous thromboembolism	45 (3.6%)	40 (4.0%)	*	*
Diabetes mellitus	41 (3.3%)	26 (2.6%)	8 (0.8%)	0 (0.0%)
Lung diseases due to external agents	13 (1.0%)	26 (2.6%)	57 (5.8%)	9 (5.3%)
Acute lower respiratory infections	22 (1.8%)	21 (2.1%)	43 (4.4%)	12 (7.1%)
Asthma and bronchiectasis	21 (1.7%)	24 (2.4%)	25 (2.6%)	7 (4.1%)
Influenza	15 (1.2%)	16 (1.6%)	17 (1.7%)	7 (4.1%)
Obstructive uropathy	9 (0.7%)	*	12 (1.2%)	5 (2.9%)
Total avoidable causes of mortality**	1,245 (100.0%)	1,001 (100.0%)	975 (100.0%)	170 (100.0%)

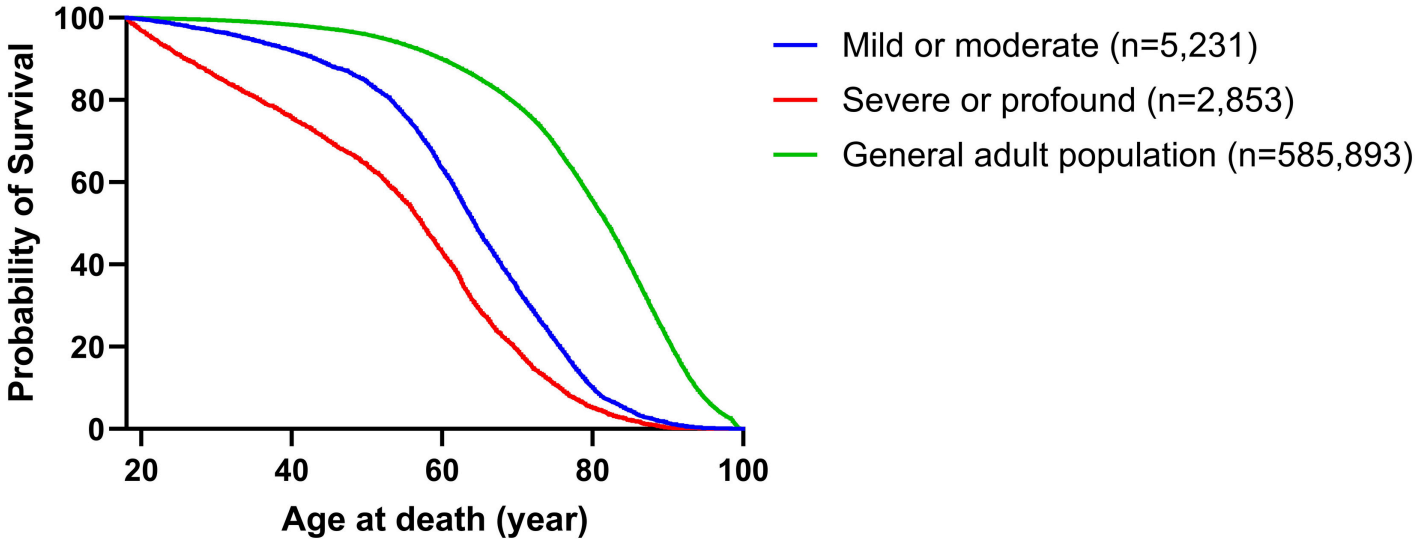
* Fewer than five cases

** Only the most common causes of death are shown in this table. Less common causes of death are not presented individually and therefore the total does not equal the total number of deaths

Appendix 2.6: *Demographics of adults with a learning disability who died between 2021 and 2024, by level of learning disability, using initial reviews.*

	Mild or moderate	Severe or profound	*p-value*
Sex registered at birth			
Female	2,225 (42.5%)	1,213 (42.5%)	0.822
Male	2,906 (55.6%)	1,591 (55.8%)	
Not known	100 (1.9%)	49 (1.7%)	
Total	5,231 (100.0%)	2,853 (100.0%)	
Ethnic group			
Asian or Asian British	144 (2.8%)	214 (7.5%)	**<0.001**
Black African, Caribbean, or Black British	115 (2.2%)	93 (3.3%)	
Mixed ethnic group	40 (0.8%)	48 (1.7%)	
Other ethnic group	22 (0.4%)	27 (0.9%)	
White	4,770 (91.2%)	2,392 (83.8%)	
Preferred not to say	140 (2.7%)	79 (2.8%)	
Total	5,231 (100.0%)	2,853 (100.0%)	

Appendix 2.7: *Survival curves of adults with a learning disability who died between 2021 and 2024, by level of learning disability, using initial reviews.*



The median age at death for adults with a severe or profound learning disability was 57.3 years (95% CI: 56.2–59.7 years), lower than for adults with a mild or moderate learning disability (64.3 years, 95% CI: 63.9–64.7 years) and the general adult population in England and Wales (2022) (81.9 years, 95% CI: 81.9–82.0 years) ($p<0.001$).

Appendix 2.8: *Long-term conditions of adults with a learning disability who died between 2021 and 2024, by level of learning disability, using initial reviews and coded data*

Long-term conditions	Mild or moderate	Severe or profound	*p-value*
Initial review data			
Physical conditions			
Asthma	832 (15.9%)	301 (10.6%)	**<0.001**
Cancer	897 (17.1%)	282 (9.9%)	**<0.001**
Cardiovascular disease	1,132 (21.6%)	323 (11.3%)	**<0.001**
Chronic kidney disease	736 (14.1%)	186 (6.5%)	**<0.001**
Deep vein thrombosis	149 (2.8%)	50 (1.8%)	**<0.01**
Dementia	874 (16.7%)	348 (12.2%)	**<0.001**
Diabetes	1,152 (22.0%)	247 (8.7%)	**<0.001**
Dysphagia	1,036 (19.8%)	1,160 (40.7%)	**<0.001**
Epilepsy	1,497 (28.6%)	1,567 (54.9%)	**<0.001**
Gastrointestinal illness	1,194 (22.8%)	914 (32.0%)	**<0.001**
Hypertension	1,262 (24.1%)	276 (9.7%)	**<0.001**
Obesity	973 (18.6%)	202 (7.1%)	**<0.001**
Sensory impairment	706 (13.5%)	587 (20.6%)	**<0.001**
Significantly underweight	285 (5.4%)	294 (10.3%)	**<0.001**
Stroke	390 (7.5%)	158 (5.5%)	**0.001**
Mean number of physical conditions (SD)	2.51 (1.73)	2.42 (1.60)	**0.021**
Mental health conditions**			
0	3,871 (74.0%)	2,548 (89.3%)	**<0.001**
≥1	1,360 (26.0%)	305 (10.7%)	
Total	5,231 (100.0%)	2,853 (100.0%)	
Coded data			
Physical conditions			
Chronic obstructive pulmonary disease	199 (7.5%)	27 (1.9%)	**<0.001**
Coronary artery disease	66 (2.5%)	5 (0.3%)	**<0.001**
Hearing problems	469 (17.7%)	196 (13.6%)	**<0.01**
Kidney problems	700 (26.4%)	271 (18.8%)	**<0.001**
Osteoporosis	90 (3.4%)	57 (4.0%)	0.358
Peripheral artery disease	18 (0.7%)	*	**0.044**
Thyroid disorder	269 (10.1%)	97 (6.7%)	**<0.01**
Visual problems	803 (30.3%)	549 (38.1%)	**<0.001**
Mental health conditions			
Anxiety	845 (31.9%)	351 (24.3%)	**<0.001**
Depression	661 (24.9%)	144 (10.0%)	**<0.001**
Psychosis	355 (13.4%)	56 (3.9%)	**<0.001**
Bipolar	123 (4.6%)	48 (3.3%)	**0.046**
Mean number of mental health conditions (SD)	0.75 (0.85)	0.42 (0.67)	**<0.001**
Total	2,652 (100.0%)	1,442 (100.0%)	

* Fewer than five cases

SD = standard deviation

**0 indicates no recorded mental health condition and ≥1 indicates one or more recorded mental health conditions. The data record only the presence or absence of a mental health condition and do not specify type.
Long-term conditions in this table are drawn from two complementary sources: initial review data, available for all LeDeR reviews completed after June 2021, and coded data, which captures additional conditions not included in the initial review — such as chronic obstructive pulmonary disease and thyroid disorders, identified as priorities by advisory board members — but is only available for a subset of reviews. Both sources are presented alongside each other to provide as complete a picture as possible, but findings from each should be interpreted within the context of their respective denominators and should not be directly compared.

Appendix 2.9: *Circumstances of death of adults with a learning disability who died between 2021 and 2024, by level of learning disability, using initial reviews.*

Circumstances at death	Group 1: Mild or moderate	Group 2: Severe or profound	*p*-value (1 vs 2)	Group 3: General adult population 2024*	*p-value (2 vs 3)*
DNACPR decision at death					
Yes	3,772 (72.1%)	2,200 (77.1%)	**<0.001**	±	-
No	1,459 (27.9%)	653 (22.9%)			
Total	5,231 (100.0%)	2,853 (100.0%)			
(If yes to above) Was the DNACPR documentation correctly completed and followed?					
Completed and followed	2,311 (61.3%)	1,353 (61.5%)	0.114	±	-
Completed but not followed correctly	35 (0.9%)	18 (0.8%)			
Incorrectly completed and followed	282 (7.5%)	183 (8.3%)			
Neither completed nor followed correctly	13 (0.3%)	17 (0.8%)			
Not known	1,131 (30.0%)	629 (28.6%)			
Total	3,772 (100.0%)	2,200 (100.0%)			
Reported to a coroner					
Yes	1,454 (27.8%)	789 (27.7%)	**<0.01**	174,878 (30.8%)	**<0.001**
No	853 (16.3%)	549 (19.2%)		393,735 (69.2%)	
Not known	2,924 (55.9%)	1,515 (53.1%)		0 (0.0%)	
Total	5,231 (100.0%)	2,853 (100.0%)		568,613 (100.0%)	
Was there a police investigation					
Yes	472 (9.0%)	233 (8.2%)	**<0.01**	±	-
No	1,835 (35.1%)	1,105 (38.7%)			
Not known	2,924 (55.9%)	1,515 (53.1%)			
Total	5,231 (100.0%)	2,853 (100.0%)			
Safeguarding concerns					
Yes	402 (7.7%)	247 (8.7%)	**0.04**	±	-
No	1,905 (36.4%)	1,091 (38.2%)			
Not known	2,924 (55.9%)	1,515 (53.1%)			
Total	5,231 (100.0%)	2,853 (100.0%)			

*Provisional, includes deaths of all ages in England and Wales.
± Data not available

Appendix 2.10: *Circumstances of death of adults with a learning disability who died between 2021 and 2024, by level of learning disability, using focused reviews.*

Reported to a coroner*	Mild or moderate	Severe or profound	*p-value*
Yes	752 (41.2%)	436 (37.6%)	0.148
No	1,045 (57.2%)	702 (60.6%)	
Not known	29 (1.6%)	21 (1.8%)	
Total	1,826 (100.0%)	1,159 (100.0%)	
Was there a police investigation?*			
Yes	63 (3.5%)	37 (3.2%)	0.782
No	1,763 (96.5%)	1,122 (96.8%)	
Total	1,826 (100.0%)	1,159 (100.0%)	
Safeguarding concerns*			
Yes	201 (11.0%)	117 (10.1%)	0.467
No	1,625 (89.0%)	1,042 (89.9%)	
Total	1,826 (100.0%)	1,159 (100.0%)	

*Sections are based on focused reviews and are included to maintain comparability with the LeDeR 2023 annual report.

Appendix 2.11: *Most common causes of death of adults with a learning disability who died between 2021 and 2024, (by ICD-10 chapter) by the level of learning disability, using initial reviews.*

Causes of death (ICD-10 chapter)	Group 1: Mild or moderate	Group 2: Severe or profound	Group 3: General adult population 2024	*p-value* (1 vs 2)	*p-value* (1 vs 3)	*p-value* (2 vs 3)
Diseases of the circulatory system	955 (18.4%)	285 (10.1%)	126,111 (23.9%)			
Neoplasms	873 (16.8%)	293 (10.4%)	142,833 (27.1%)			
Diseases of the respiratory system	817 (15.7%)	471 (16.7%)	64,108 (12.1%)			
Congenital malformations	583 (11.2%)	416 (14.7%)	1,169 (0.2%)			
Diseases of the nervous system	508 (9.8%)	629 (22.3%)	41,942 (7.9%)			
Diseases of the digestive system	371 (7.1%)	201 (7.1%)	28,228 (5.3%)	**<0.001**	**<0.001**	**<0.001**
External causes of morbidity and mortality*	199 (3.8%)	73 (2.6%)	24,646 (4.7%)			
Mental and behavioural disorders**	195 (3.8%)	101 (3.6%)	40,850 (7.7%)			
Endocrine and metabolic diseases	145 (2.8%)	65 (2.3%)	9,958 (1.9%)			
Provisional assignment of new diseases***	143 (2.8%)	92 (3.3%)	6,140 (1.2%)			
Total known causes of mortality******	5,189 (100.0%)	2,827 (100.0%)	527,747 (100.0%)			

*External causes of morbidity and mortality (ICD-10 Chapter XX) include deaths resulting from injuries or other external events, such as accidents, exposure to harmful substances, or intentional self-harm.

**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).

**** Only the most common causes of death are shown in this table. Less common causes of death are not presented individually and therefore the total does not equal the total number of deaths

Appendix 2.12: *Most common underlying ICD-10 code causes of death of adults with a learning disability who died between 2021 and 2024, by level of learning disability, using initial reviews.*

Causes of death (ICD-10 chapter)	Mild or moderate	Severe or profound
Diseases of the nervous system	508 (9.8%)	629 (22.3%)
Cerebral palsy, unspecified**	90 (1.7%)	303 (10.7%)
Epilepsy, unspecified	141 (2.7%)	130 (4.6%)
Other cerebral palsy	*	22 (0.8%)
Diseases of the respiratory system	817 (15.7%)	471 (16.7%)
Pneumonia, unspecified	257 (5.0%)	150 (5.3%)
Pneumonitis due to food and vomit	58 (1.1%)	74 (2.6%)
Bronchopneumonia, unspecified	117 (2.3%)	68 (2.4%)
Unspecified acute lower respiratory infection	75 (1.4%)	68 (2.4%)
Congenital malformations	583 (11.2%)	416 (14.7%)
Down syndrome, unspecified**	458 (8.8%)	250 (8.8%)
Microcephaly	*	21 (0.7%)
Tuberous sclerosis	*	15 (0.5%)
Neoplasms	873 (16.8%)	293 (10.4%)
Breast, unspecified	68 (1.3%)	32 (1.1%)
Colon, unspecified	41 (0.8%)	24 (0.8%)
Malignant neoplasm, primary site unknown, so stated	59 (1.1%)	16 (0.6%)
Oesophagus, unspecified	55 (1.1%)	16 (0.6%)
Diseases of the circulatory system	955 (18.4%)	285 (10.1%)
Stroke, not specified as haemorrhage or infarction	87 (1.7%)	37 (1.3%)
Atherosclerotic heart disease	103 (2.0%)	31 (1.1%)
Acute myocardial infarction, unspecified	117 (2.3%)	27 (1.0%)
Diseases of the digestive system	371 (7.1%)	201 (7.1%)
Volvulus	38 (0.7%)	37 (1.3%)
Other and unspecified intestinal obstruction	38 (0.7%)	32 (1.1%)
Gastrointestinal haemorrhage, unspecified	17 (0.3%)	11 (0.4%)
Mental and behavioural disorders* **	195 (3.8%)	101 (3.6%)
Unspecified dementia	134 (2.6%)	40 (1.4%)
Developmental disorder of scholastic skills, unspecified	8 (0.2%)	29 (1.0%)
Rett syndrome	*	13 (0.5%)

Provisional assignment of new diseases**	143 (2.8%)	92 (3.3%)
COVID-19, virus identified	141 (2.7%)	89 (3.1%)
External causes of morbidity and mortality***	199 (3.8%)	73 (2.6%)
Inhalation and ingestion of food causing obstruction of respiratory tract	32 (0.6%)	14 (0.5%)
Inhalation and ingestion of other objects causing obstruction of respiratory tract	8 (0.2%)	10 (0.4%)
Sequelae of motor-vehicle accident	*	6 (0.2%)
Exposure to unspecified factor causing fracture	13 (0.3%)	6 (0.2%)
Endocrine and metabolic diseases	145 (2.8%)	65 (2.3%)
Other sphingolipidosis	5 (0.1%)	7 (0.2%)
Volume depletion	0 (0.0%)	5 (0.2%)
Other hyperphenylalaninaemias	*	*
Total known causes of mortality****	5,189 (100.0%)	2,827 (100.0%)

* Fewer than five cases
**Although Down syndrome and cerebral palsy should not be listed as the sole cause of death on the MCCD, 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).
***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).
*****External causes of morbidity and mortality (ICD-10 Chapter XX) include deaths resulting from injuries or other external events, such as accidents, exposure to harmful substances, or intentional self-harm.
****** Only the most common causes of death are shown in this table. Less common causes of death are not presented individually and therefore the total does not equal the total number of deaths

Appendix 2.13: *Avoidable mortality of adults with a learning disability who died between 2021 and 2024, by level of learning disability, using initial reviews.*

Avoidable mortality	Group 1: Mild or moderate	Group 2: Severe or profound	Group 3: General adult population 2024	*p-value* (1 vs 2)	*p-value* (1 vs 3)	*p-value* (2 vs 3)
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%)	**0.016**	**<0.001**	**<0.001**
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%)	**<0.001**	**<0.001**	0.779
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%)	**0.018**	**<0.001**	**<0.001**
Total known causes of mortality	5,189 (100.0%)	2,827 (100.0%)	527,747 (100.0%)			

Appendix 2.14: *Most common avoidable causes of mortality of adults with a learning disability who died between 2021 and 2024 (by OECD classification), by level of learning disability, using initial reviews.*

Avoidable causes of mortality (by OECD classification)	Group 1: Mild or moderate	Group 2: Severe or profound	Group 3: General adult population 2024	*p-value* (1 vs 2)	*p-value* (1 vs 3)	*p-value* (2 vs 3)
Pneumonia, not elsewhere classified or organism unspecified	255 (11.4%)	190 (16.6%)	3,270 (2.9%)			
Ischaemic heart diseases	244 (10.9%)	60 (5.2%)	19,386 (17.4%)			
Cerebrovascular diseases	153 (6.8%)	91 (7.9%)	6,229 (5.6%)			
Epilepsy	143 (6.4%)	154 (13.4%)	551 (0.5%)			
COVID-19	113 (5.0%)	76 (6.6%)	1,131 (1.0%)			
Accidental injuries	110 (4.9%)	41 (3.6%)	6,601 (5.9%)			
Colorectal cancer	105 (4.7%)	40 (3.5%)	6,092 (5.5%)	**<0.001**	**<0.001**	**<0.001**
Chronic lower respiratory diseases	102 (4.5%)	7 (0.6%)	8,771 (7.9%)			
Venous thromboembolism	85 (3.8%)	23 (2.0%)	2,115 (1.9%)			
Diabetes mellitus	67 (3.0%)	8 (0.7%)	2,234 (2.0%)			
Lung diseases due to external agents	39 (1.7%)	66 (5.8%)	263 (0.2%)			
Acute lower respiratory infections	43 (1.9%)	55 (4.8%)	431 (0.4%)			
Asthma and bronchiectasis	45 (2.0%)	32 (2.8%)	631 (0.6%)			
Total avoidable causes of mortality	2,246 (100.0%)	1,145 (100.0%)	111,614 (100.0%)			

Appendix 2.15: *Quality of care of adults with a learning disability who died between 2021 and 2024, by level of learning disability, using initial reviews.*

Quality of care	Mild or moderate	Severe or profound	*p-value*
Good practice identified			
Yes	3,558 (68.0%)	2,041 (71.5%)	**0.012**
No	1,673 (32.0%)	812 (28.5%)	
Total	5,231 (100.0%)	2,853 (100.0%)	
Concerns identified			
Yes	599 (11.5%)	317 (11.1%)	0.861
No	3,232 (61.8%)	1,778 (62.3%)	
Not known	1,400 (26.8%)	758 (26.6%)	
Total	5,231 (100.0%)	2,853 (100.0%)	
Use of the Mental Capacity Act			
Correctly followed	3,311 (63.3%)	2,118 (74.2%)	**<0.001**
Not correctly followed	343 (6.6%)	194 (6.8%)	
Not known	1,577 (30.1%)	541 (19.0%)	
Total	5,231 (100.0%)	2,853 (100.0%)	

Appendix 2.16: *Quality of care of adults with a learning disability who died between 2021 and 2024 by level of learning disability using focused reviews.*

Quality of care	Mild or moderate	Severe or profound	*p-value*
Concerns identified*			
Yes	604 (33.1%)	349 (30.1%)	0.209
No	1,157 (63.4%)	771 (66.5%)	
Not known	65 (3.6%)	39 (3.4%)	
Total	1,826 (100.0%)	1,159 (100.0%)	
Care package met the needs of the person			
Yes	1,322 (72.4%)	961 (82.9%)	**<0.001**
No	504 (27.6%)	198 (17.1%)	
Total	1,826 (100.0%)	1,159 (100.0%)	
Reasonable adjustments made			
All reasonable adjustments provided	1,319 (72.2%)	883 (76.2%)	**0.017**
Reasonable adjustments should have been provided but were not	507 (27.8%)	276 (23.8%)	
Total	1,826 (100.0%)	1,159 (100.0%)	

*Sections are based on focused reviews and are included to maintain comparability with the LeDeR 2023 annual report.

Appendix 2.17: *Qualitative framework analysis of problems with care for adults with a severe or profound learning disability who died between 2021 and 2024, using focused reviews.*

Delays in care

What

Deterioration in physical health was not always recognised or escalated promptly. Investigations, referrals and specialist reviews were often delayed.

- Investigations and screening
- Recognising deterioration
- Specialist referral and review

"There was a delay in him having repeat bloods done due to the waiting time for a district nurse to attend the home"

"Changes in physical health, mobility, pain, breathing, and cognition were not always recognised or escalated"

Where

Delays in preventative care, emergency assessment, imaging, escalation, treatment, and discharge planning were commonly identified.

- Primary care
- Acute hospital and ambulance services
- Community learning disability team

*"The annual learning disability health checks / GP visits did not identify any strategies for coping with ******'s obesity"*

"Delayed involvement from CLDTs affected reassessment, care planning, and coordination of specialist support"

When

Early opportunities to recognise deterioration and escalate care were sometimes missed. Delays during admission and diagnostic pathways were often prolonged, fragmented or incomplete.

- Initial contact with NHS 111
- Emergency admission to hospital
- Assessment and diagnostic stages

"There was a significant delay in diagnosis, which led to a delay in available support and treatment"

"An ambulance was called at 16.28... did not reach the emergency department until 22.22"

Gaps in care

What

Preventative healthcare and reasonable adjustments were inconsistently implemented. Health promotion, desensitisation, and MDT support were often absent.

- Preventative care & reasonable adjustments
- Monitoring and reassessment of complex conditions
- Coordinated MDT care

*"The reasonable adjustments that ******* may have required to access health checks were not recorded or actioned"*

"There was no evidence of monitoring of this condition or guidance with regards possible deterioration"

Where

Residential settings frequently struggled to meet changing physical and behavioural support needs. CLDT involvement was inconsistent.

- Residential and nursing care
- Community learning disability teams
- Social care

*"***** spent over 5 months in bed without leaving her bedroom with little stimulation or social interaction"*

"No mention of reasonable adjustments, or LD liaison support "

When

Anticipatory care planning and community-based EOL support often occurred late or were absent. Opportunities to intervene during the escalation of deteriorating health were frequently missed.

- End-of-life care plan
- Periods of escalating risk
- Accessing emergency care

" Risk was not assessed... Had it been assessed it may have led to identification and treatment of her condition and prevention of her early death"

"End of life care was not facilitated in the community"

Problems with organisational systems

What

Poor communication and fragmented systems contributed to care failures. Specialist guidance and recommendations were not consistently followed.

Lack of communication between services	Non-adherence to care plans and specialist guidance	Inadequate community staffing and provision

"Use of the RESTORE2 tool could have given staff confidence to call 999"

"Poor social care coordination... in regard to personal care, finances and mental capacity, including a lack of professional curiosity"

Where

Challenges during acute admissions included poor coordination, communication, and escalation. Residential and supported living placements often struggled to manage complex needs.

Residential care	Emergency admission to acute hospital wards

"Her learning disability needs were not fully acknowledged on admission to hospital"

"Care package from supported living was not sufficient"

When

During periods of rapid deterioration and transitions between services, including reassessment of changing needs and the coordination of care.

Emergency deterioration	Discharge planning and transitions between services	Long-term management of complex health needs

"Risk assessments were not carried out... Not referred to the CLDT... "

"Red flags indicating critical care not followed, communication on discharge from hospital ward care and urgent referral missed and not followed up"

Diagnosis & treatment guidelines not met

What

Investigations were delayed, incomplete, or not adapted to meet communication and behavioural needs. Monitoring of epilepsy, cardiology, nutrition, and chronic conditions was inconsistent.

Delayed or incomplete diagnostic investigations	Inadequate long-term condition monitoring	Reasonable adjustments and specialist reviews not provided

"There was no evidence of medication reviews"

"Guidelines associated with malnutrition, dehydration, falls, cardiopulmonary resuscitation, management of hypertension prevention of venous thrombosis not followed"

Where

Clinical needs were not consistently identified, monitored or managed in line with clinical guidance, particularly across primary care, hospital, community and specialist services.

Acute hospital services	Primary care	Community and specialist services

"Needs were not consistently identified, monitored or treated in line with clinical guidance"

"Professional curiosity was lacking and further investigations were not undertaken"

When

During routine monitoring and review of long-term conditions, specialist investigations, reasonable adjustments or coordinated specialist follow-up.

During deterioration and hospital admission	Long term condition management, routine review	When needing adjustments, or follow-up

"Cardiology input with pacemaker... but did not have any input from cardiologist since 2015"

*"There was no evidence of any reasonable adjustments that were attempted/provided to ensure ***** received this investigation"*

Chapter 3

Appendix 3.1: *Demographics of adults with Down syndrome and other adults with a learning disability who died between 2021 and 2024, using initial reviews.*

Demographics	Adults with Down syndrome	Other adults with a learning disability	*p*-value
Sex registered at birth			
Female	876 (44.1%)	4,120 (42.5%)	0.29
Male	1,080 (54.4%)	5,404 (55.7%)	
Not known	30 (1.5%)	177 (1.8%)	
Total	1,986 (100.0%)	9,701 (100.0%)	
Ethnic group			
Asian or Asian British	42 (2.1%)	332 (3.4%)	**<0.01**
Black African, Caribbean, or Black British	36 (1.8%)	190 (2.0%)	
Mixed ethnic group	15 (0.8%)	81 (0.8%)	
Other ethnic group	*	48 (0.5%)	
Preferred not to say	43 (2.2%)	285 (2.9%)	
White	1,840 (92.6%)	8,753 (90.2%)	
Not known	*	12 (0.1%)	
Total	1,986 (100.0%)	9,701 (100.0%)	

* Fewer than five cases

Appendix 3.2: *Long-term conditions in adults with Down syndrome and other adults with a learning disability who died between 2021 and 2024, using initial reviews, and coded data.*

Long-term conditions	Adults with Down syndrome	Other adults with a learning disability	*p-value*
Initial review data			
Physical conditions			
Dementia	791 (39.8%)	499 (5.1%)	**<0.001**
Epilepsy	591 (29.8%)	2,599 (26.8%)	**<0.01**
Dysphagia	499 (25.1%)	1,779 (18.3%)	**<0.001**
Cardiovascular disease	258 (13.0%)	1,304 (13.4%)	0.591
Sensory impairment	257 (12.9%)	1,096 (11.3%)	**0.041**
Gastrointestinal illness	215 (10.8%)	1,893 (19.5%)	**<0.001**
Obesity	186 (9.4%)	1,065 (11.0%)	**0.037**
Chronic kidney disease	151 (7.6%)	839 (8.6%)	0.127
Diabetes	133 (6.7%)	1,366 (14.1%)	**<0.001**
Asthma	124 (6.2%)	1,077 (11.1%)	**<0.001**
Hypertension	91 (4.6%)	1,557 (16.0%)	**<0.001**
Stroke	76 (3.8%)	513 (5.3%)	**<0.01**
Significantly underweight	75 (3.8%)	535 (5.5%)	**<0.01**
Cancer	66 (3.3%)	1,178 (12.1%)	**<0.001**
Deep vein thrombosis	41 (2.1%)	169 (1.7%)	0.324
Mean number of physical conditions (SD)	2.00 (1.99)	1.91 (1.91)	0.128
Mental health conditions*			
0	1,847 (93.0%)	8,090 (83.4%)	**<0.001**
≥1	139 (7.0%)	1,611 (16.6%)	
Total	1,986 (100.0%)	9,701 (100.0%)	
Coded data			
Physical conditions			
Visual problems	465 (36.5%)	1,788 (29.5%)	**<0.001**
Hearing problems	288 (22.6%)	876 (14.5%)	**<0.001**
Kidney problems	255 (20.0%)	1,397 (23.1%)	**0.018**
Thyroid disorders	154 (12.1%)	229 (3.8%)	**<0.001**
Osteoporosis	46 (3.6%)	306 (5.1%)	**0.029**
Chronic obstructive pulmonary disease	19 (1.5%)	385 (6.4%)	**<0.001**
Coronary artery disease	9 (0.7%)	65 (1.1%)	0.234
Peripheral artery disease	6 (0.5%)	15 (0.2%)	0.175
Mental health conditions			
Anxiety	283 (22.2%)	1,652 (27.3%)	**<0.001**
Bipolar	13 (1.0%)	269 (4.4%)	**<0.001**
Depression	200 (15.7%)	1,111 (18.3%)	**0.025**
Psychosis	47 (3.7%)	619 (10.2%)	**<0.001**
Mean number of mental health conditions (SD)	0.43 (0.67)	0.60 (0.80)	**<0.001**
Total	1,274 (100.0%)	6,057 (100.0%)	

SD = standard deviation

*0 indicates no recorded mental health condition and ≥1 indicates one or more recorded mental health conditions. The data record only the presence or absence of a mental health condition and do not specify type.

Long-term conditions in this table are drawn from two complementary sources: initial review data, available for all LeDeR reviews completed after June 2021, and coded data, which captures additional conditions not included in the initial review — such as chronic obstructive pulmonary disease and thyroid disorders, identified as priorities by advisory board members — but is only available for a subset of reviews. Both sources are presented alongside each other to provide as complete a picture as possible, but findings from each should be interpreted within the context of their respective denominators and should not be directly compared.

Appendix 3.3: *Circumstances of death of adults with Down syndrome and other adults with a learning disability who died between 2021 and 2024, using initial reviews.*

Circumstances at death	Group 1: Adults with Down syndrome	Group 2: Other adults with a learning disability	*p*-value (1 vs 2)	Group 3: General adult population 2024*	*p*-value (1 vs 3)
DNACPR decision at death					
Yes	1,660 (83.6%)	6,958 (71.7%)			
No	326 (16.4%)	2,743 (28.3%)	**<0.001**	±	-
Total	1,986 (100.0%)	9,701 (100.0%)			
(If yes to above) Was the DNACPR documentation correctly completed and followed?					
Completed and followed	1,017 (61.3%)	4,272 (61.4%)			
Completed but not followed correctly	10 (0.6%)	74 (1.1%)			
Incorrectly completed and followed	116 (7.0%)	502 (7.2%)			
Neither completed nor followed correctly	6 (0.4%)	39 (0.6%)	0.289	±	-
Not known	511 (30.8%)	2,071 (29.8%)			
Total	1,660 (100.0%)	6,958 (100.0%)			
Reported to a coroner					
Yes	359 (18.1%)	2,719 (28.0%)		174,878 (30.8%)	
No	409 (20.6%)	1,680 (17.3%)	**<0.001**	393,735 (69.2%)	**<0.001**
Not known	1,218 (61.3%)	5,302 (54.7%)		0 (0.0%)	
Total	1,986 (100.0%)	9,701 (100.0%)		568,613 (100.0%)	
Was there a police investigation?					
Yes	92 (4.6%)	842 (8.7%)			
No	676 (34.0%)	3,557 (36.7%)	**<0.001**	±	-
Not known	1,218 (61.3%)	5,302 (54.7%)			
Total	1,986 (100.0%)	9,701 (100.0%)			
Safeguarding concerns					
Yes	106 (5.3%)	756 (7.8%)			
No	662 (33.3%)	3,643 (37.6%)	**<0.001**	±	-
Not known	1,218 (61.3%)	5,302 (54.7%)			
Total	1,986 (100.0%)	9,701 (100.0%)			

*Provisional data, includes deaths of all ages in England and Wales.
± Data not available

Appendix 3.4: *Circumstances of death of adults with Down syndrome and other adults with learning disability who died between 2021 and 2024 using focused reviews.*

Circumstances at death	Adults with Down syndrome	Other adults with a learning disability	*p-value*
Reported to a coroner*			
Yes	138 (29.1%)	1,125 (41.8%)	**<0.001**
No	330 (69.5%)	1,514 (56.3%)	
Not known	7 (1.5%)	50 (1.9%)	
Total	475 (100.0%)	2,689 (100.0%)	
Was there a police investigation?*			
Yes	12 (2.5%)	94 (3.5%)	0.345
No	463 (97.5%)	2,595 (96.5%)	
Total	475 (100.0%)	2,689 (100.0%)	
Safeguarding concerns*			
Yes	50 (10.5%)	282 (10.5%)	1
No	425 (89.5%)	2,407 (89.5%)	
Total	475 (100.0%)	2,689 (100.0%)	

*Sections are based on focused reviews and are included to maintain comparability with the LeDeR 2023 annual report.

Appendix 3.5: *Most common causes of death (by ICD-10 chapter) for adults with Down syndrome and other adults with a learning disability who died between 2021 and 2024 using original* ICD-10 codes using initial reviews.*

Causes of death (ICD-10 chapter)	Group 1: Adults with Down syndrome	Group 2: Other adults with a learning disability	Group 3: General adult population 2024	*p-value* (1 vs 2)	*p-value* (1 vs 3)	*p-value* (2 vs 3)
Congenital malformations, deformations and chromosomal abnormalities	1,093 (55.3%)	353 (3.7%)	1,169 (0.2%)			
Down syndrome unspecified	1,052 (53.2%)	0 (0.0%)	378 (0.1%)			
Other specified congenital malformations of heart	13 (0.7%)	25 (0.3%)	71 (0.0%)			
Atrioventricular Septal Defect	7 (0.4%)	0 (0.0%)	8 (0.0%)			
Diseases of the circulatory system	189 (9.6%)	1,689 (17.5%)	126,111 (23.9%)			
Diseases of the respiratory system	139 (7.0%)	1,630 (16.9%)	64,108 (12.1%)			
Diseases of the nervous system	116 (5.9%)	1,433 (14.9%)	41,942 (7.9%)	**<0.001**	**<0.001**	**<0.001**
Provisional assignment of new diseases**	114 (5.8%)	452 (4.7%)	6,140 (1.2%)			
Neoplasms	80 (4.0%)	1,596 (16.6%)	142,833 (27.1%)			
Mental and behavioural disorders***	69 (3.5%)	388 (4.0%)	40,850 (7.7%)			
Diseases of the digestive system	61 (3.1%)	741 (7.7%)	28,228 (5.3%)			
External causes of morbidity and mortality******	29 (1.5%)	325 (3.4%)	24,646 (4.7%)			
Diseases of the genitourinary system	29 (1.5%)	260 (2.7%)	8,359 (1.6%)			
Total known causes of mortality*******	1,978 (100.0%)	9,626 (100.0%)	527,747 (100.0%)			

*See Methods section for details on the original and updated ICD-10 coding approach used in this analysis.
**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).
***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.
****External causes of morbidity and mortality (ICD-10 Chapter XX) includes deaths resulting from injuries or other external events, such as accidents, exposure to harmful substances, or intentional self-harm.
***** Only the most common causes of death are shown in this table. Less common causes of death are not presented individually and therefore the total does not equal the total number of deaths

Appendix 3.6: *Most common causes of death (by ICD-10 chapter) for adults with Down syndrome and other adults with a learning disability, who died between 2021 and 2024, using updated* ICD-10 codes from initial reviews.*

Causes of death (ICD-10 chapter)	Group 1: Adults with Down syndrome	Group 2: Other adults with a learning disability	Group 3: General adult population 2024	*p-value* (1 vs 2)	*p-value* (1 vs 3)	*p-value* (2 vs 3)
Diseases of the nervous system	471 (23.8%)	1,433 (14.9%)	41,942 (7.9%)	**<0.001**	**<0.001**	**<0.001**
Mental and behavioural disorders**	383 (19.4%)	388 (4.0%)	40,850 (7.7%)			
Diseases of the circulatory system	257 (13.0%)	1,689 (17.5%)	126,111 (23.9%)			
Diseases of the respiratory system	244 (12.3%)	1,630 (16.9%)	64,108 (12.1%)			
Provisional assignment of new diseases***	119 (6.0%)	452 (4.7%)	6,140 (1.2%)			
Neoplasms	83 (4.2%)	1,596 (16.6%)	142,833 (27.1%)			
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	83 (4.2%)	117 (1.2%)	18,693 (3.5%)			
Diseases of the digestive system	66 (3.3%)	741 (7.7%)	28,228 (5.3%)			
Endocrine, nutritional and metabolic diseases	63 (3.2%)	267 (2.8%)	9,958 (1.9%)			
Diseases of the genitourinary system	62 (3.1%)	260 (2.7%)	8,359 (1.6%)			
Total known causes of mortality****	1,977 (100.0%)	9,626 (100.0%)	527,747 (100.0%)			

*See Methods section for details on the updated ICD-10 coding approach used in this analysis.
**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).
**** Only the most common causes of death are shown in this table. Less common causes of death are not presented individually and therefore the total does not equal the total number of deaths

Appendix 3.7: *Most common underlying ICD-10 code causes of death for adults with Down syndrome and other adults with a learning disability, who died between 2021 and 2024, using initial reviews.*

Causes of death (ICD-10 chapter)	Adults with Down syndrome	Other adults with a learning disability
Diseases of the nervous system	471 (23.8%)	1,433 (14.9%)
Alzheimer disease with early onset	197 (10.0%)	14 (0.1%)
Epilepsy, unspecified	174 (8.8%)	320 (3.3%)
Alzheimer disease, unspecified	62 (3.1%)	54 (0.6%)
Mental and behavioural disorders**	383 (19.4%)	388 (4.0%)
Unspecified dementia	343 (17.3%)	203 (2.1%)
Developmental disorder of scholastic skills, unspecified	25 (1.3%)	73 (0.8%)
Vascular dementia, unspecified	10 (0.5%)	57 (0.6%)
Diseases of the circulatory system	257 (13.0%)	1,689 (17.5%)
Stroke, not specified as haemorrhage or infarction	32 (1.6%)	171 (1.8%)
Other specified pulmonary heart diseases	21 (1.1%)	0 (0.0%)
Acute myocardial infarction, unspecified	19 (1.0%)	208 (2.2%)
Diseases of the respiratory system	244 (12.3%)	1,630 (16.9%)
Pneumonia, unspecified	80 (4.0%)	508 (5.3%)
Pneumonitis due to food and vomit	36 (1.8%)	171 (1.8%)
Bronchopneumonia, unspecified	33 (1.7%)	251 (2.6%)
Provisional assignment of new diseases***	119 (6.0%)	452 (4.7%)
COVID-19, virus identified	118 (6.0%)	446 (4.6%)
COVID-19, virus not identified	0 (0.0%)	*
Neoplasms	83 (4.2%)	1,596 (16.6%)
Primary site unknown, so stated	9 (0.5%)	91 (0.9%)
Bladder, unspecified	7 (0.4%)	69 (0.7%)
Breast, unspecified	6 (0.3%)	134 (1.4%)
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	83 (4.2%)	117 (1.2%)
Other specified general symptoms and signs	51 (2.6%)	58 (0.6%)
Dysphagia	13 (0.7%)	0 (0.0%)
Other and unspecified convulsions	6 (0.3%)	0 (0.0%)
Diseases of the digestive system	66 (3.3%)	741 (7.7%)
Other and unspecified intestinal obstruction	8 (0.4%)	85 (0.9%)
Umbilical hernia with obstruction, without gangrene	5 (0.3%)	5 (0.1%)
Volvulus	*	101 (1.0%)
Endocrine, nutritional and metabolic diseases	63 (3.2%)	267 (2.8%)
Hypothyroidism, unspecified	20 (1.0%)	*
Type 2 diabetes mellitus without complications	10 (0.5%)	11 (0.1%)
Type 1 diabetes mellitus without complications	6 (0.3%)	*
Diseases of the genitourinary system	62 (3.1%)	260 (2.7%)
Urinary tract infection, site not specified	24 (1.2%)	132 (1.4%)
Chronic kidney disease, unspecified	18 (0.9%)	11 (0.1%)
Acute renal failure, unspecified	*	*

Total known causes of mortality**	1,977 (100.0%)	9,626 (100.0%)

* Fewer than five cases
**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).
**** Only the most common causes of death are shown in this table. Less common causes of death are not presented individually and therefore the total does not equal the total number of deaths

Appendix 3.8: *Avoidable mortality for adults with Down syndrome and other adults with a learning disability, who died between 2021 and 2024, using original* ICD-10 codes from initial reviews.*

Avoidable mortality	Group 1: Adults with Down syndrome	Group 2: Other adults with a learning disability	Group 3: General adult population 2024	*p-value* (1 vs 2)	*p-value* (1 vs 3)	*p-value* (2 vs 3)
Avoidable (preventable and treatable) (95% CI)	553 (28.0%) (26.0–29.9%)	4,381 (45.5%) (44.5–46.5%)	111,614 (21.1%) (21.0–21.3%)	**<0.001**	**<0.001**	**<0.001**
Preventable (95% CI)	254.5 (12.9%) (11.4–14.3%)	1,809.5 (18.8%) (18.0–19.6%)	71,426.5 (13.5%) (13.4–13.6%)	**<0.001**	0.386	**<0.001**
Treatable (95% CI)	298.5 (15.1%) (13.5–16.7%)	2,571.5 (26.7%) (25.8–27.6%)	40,187.5 (7.6%) (7.5–7.7%)	**<0.001**	**<0.001**	**<0.001**
Total known causes of mortality	1,978 (100.0%)	9,626 (100.0%)	527,747 (100.0%)			

*See Methods section for details on the original and updated ICD-10 coding approach used in this analysis.

Appendix 3.9: *Avoidable mortality for adults with Down syndrome and other adults with a learning disability, who died between 2021 and 2024, using updated* ICD-10 codes from initial reviews.*

Avoidable mortality	Group 1: Adults with Down syndrome	Group 2: Other adults with a learning disability	Group 3: General adult population 2024	*p-value* (1 vs 2)	*p-value* (1 vs 3)	*p-value* (2 vs 3)
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%)	0.23	**<0.001**	**<0.001**
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%)	**<0.01**	**<0.01**	**<0.001**
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%)	**<0.001**	**<0.001**	**<0.001**
Total known causes of mortality	1,977 (100.0%)	9,626 (100.0%)	527,747 (100.0%)			

*See Methods section for details on the updated ICD-10 coding approach used in this analysis.

Appendix 3.10: *Most common causes of avoidable mortality (by OECD classification) for adults with Down syndrome and other adults with a learning disability, who died between 2021 and 2024, using original* ICD-10 codes from initial reviews.*

Avoidable causes of death (by OECD classification)	Group 1: Adults with Down syndrome	Group 2: Other adults with a learning disability	Group 3: General adult population 2024	*p-value* (1 vs 2)	*p-value* (1 vs 3)	*p-value* (2 vs 3)
COVID-19	110 (19.9%)	342 (7.8%)	1,131 (1.0%)			
Cerebrovascular diseases	68 (12.3%)	302 (6.9%)	6,229 (5.6%)			
Pneumonia, not elsewhere classified or organism unspecified	55 (9.9%)	557 (12.7%)	3,270 (2.9%)			
Epilepsy	37 (6.7%)	350 (8.0%)	551 (0.5%)			
Congenital malformations of the circulatory system (heart defects)	35 (6.3%)	49 (1.1%)	261 (0.2%)			
Ischaemic heart diseases	34 (6.1%)	451 (10.3%)	19,386 (17.4%)			
Accidental injuries	22 (4.0%)	177 (4.0%)	6,601 (5.9%)			
Venous thromboembolism	20 (3.6%)	142 (3.2%)	2,115 (1.9%)	**<0.001**	**<0.001**	**<0.001**
Influenza	16 (2.9%)	42 (1.0%)	522 (0.5%)			
Asthma and bronchiectasis	14 (2.5%)	87 (2.0%)	631 (0.6%)			
Abdominal hernia	13 (2.4%)	48 (1.1%)	313 (0.3%)			
Lung diseases due to external agents	12 (2.2%)	124 (2.8%)	263 (0.2%)			
Acute lower respiratory infections	11 (2.0%)	119 (2.7%)	431 (0.4%)			
Total avoidable causes of mortality**	553 (100.0%)	4,381 (100.0%)	111,614 (100.0%)			

*See Methods section for details on the original and updated ICD-10 coding approach used in this analysis.
** Only the most common causes of death are shown in this table. Less common causes of death are not presented individually and therefore the total does not equal the total number of deaths

Appendix 3.11: *Most common causes of avoidable mortality (by OECD classification), for adults with Down syndrome and other adults with a learning disability, who died between 2021 and 2024, using updated* ICD-10 codes from initial reviews.*

Avoidable causes of mortality (by OECD classification)	Group 1: Adults with Down syndrome	Group 2: Other adults with a learning disability	Group 3: General adult population 2024	*p-value* (1 vs 2)	*p-value* (1 vs 3)	*p-value* (2 vs 3)
Epilepsy	178 (19.2%)	350 (8.0%)	551 (0.5%)			
COVID-19	115 (12.4%)	342 (7.8%)	1,131 (1.0%)			
Pneumonia, not elsewhere classified or organism unspecified	114 (12.3%)	557 (12.7%)	3,270 (2.9%)			
Cerebrovascular diseases	84 (9.0%)	302 (6.9%)	6,229 (5.6%)			
Congenital malformations of the circulatory system (heart defects)	54 (5.8%)	49 (1.1%)	261 (0.2%)			
Ischaemic heart diseases	41 (4.4%)	453 (10.3%)	19,386 (17.4%)	**<0.001**	**<0.001**	**<0.001**
Lung diseases due to external agents	37 (4.0%)	124 (2.8%)	263 (0.2%)			
Renal failure	27 (2.9%)	21 (0.5%)	203 (0.2%)			
Accidental injuries	25 (2.7%)	177 (4.0%)	6,601 (5.9%)			
Diabetes mellitus	25 (2.7%)	88 (2.0%)	2,234 (2.0%)			
Venous thromboembolism	25 (2.7%)	142 (3.2%)	2,115 (1.9%)			
Total avoidable causes of mortality**	929 (100.0%)	4,381 (100.0%)	111,614 (100.0%)			

*See Methods section for details on the updated ICD-10 coding approach used in this analysis.
** Only the most common causes of death are shown in this table. Less common causes of death are not presented individually and therefore the total does not equal the total number of deaths

Appendix 3.12: *Avoidable COVID-19 deaths (by OECD classification), in adults with Down syndrome and other adults with a learning disability, who died between 2021 and 2024, using updated** ICD-10 codes from initial reviews.*

Avoidable causes of mortality (by OECD classification)	2021	2022	2023	2024
Group 1: Adults with Down syndrome				
COVID-19	75 (27.9%)	28 (10.9%)	8 (3.8%)	*^
Other avoidable causes of mortality	194 (72.1%)	230 (89.1%)	201 (96.2%)	*
Total avoidable causes of mortality	269 (100.0%)	258 (100.0%)	209 (100.0%)	193 (100.0%)
Group 2: Other adults with a learning disability				
COVID-19	200 (18.5%)	95 (7.8%)	29 (2.6%)	18 (1.9%)
Other avoidable causes of mortality	882 (81.5%)	1,117 (92.2%)	1,105 (97.4%)	935 (98.1%)
Total avoidable causes of mortality	1,082 (100.0%)	1,212 (100.0%)	1,134 (100.0%)	953 (100.0%)
Group 3: General adult population				
COVID-19	20,818 (16.1%)	4,737 (4.1%)	2,007 (1.7%)	1,131 (1.0%)
Other avoidable causes of mortality	108,266 (83.9%)	111,122 (95.9%)	113,584 (98.3%)	110,483 (99.0%)
Total avoidable causes of mortality	129,084 (100.0%)	115,859 (100.0%)	115,591 (100.0%)	111,614 (100.0%)

* Fewer than five cases

**See Methods section for details on the updated ICD-10 coding approach used in this analysis.

^The proportion of COVID-19 deaths in adults with Down syndrome in 2024 remained higher than in other adults with a learning disability, albeit the absolute number was small (fewer than 5).

Appendix 3.13: *Quality of care for adults with Down syndrome and other adults with a learning disability, who died between 2021 and 2024, using initial reviews.*

Quality of care	Adults with Down syndrome	Other adults with a learning disability	*p-value*
Good practice identified			
Yes	1,330 (67.0%)	6,431 (66.3%)	0.561
No	656 (33.0%)	3,270 (33.7%)	
Total	1,986 (100.0%)	9,701 (100.0%)	
Concerns identified			
Yes	250 (12.6%)	1,411 (14.5%)	**<0.001**
No	1,284 (64.7%)	5,534 (57.0%)	
Not known	452 (22.8%)	2,756 (28.4%)	
Total	1,986 (100.0%)	9,701 (100.0%)	
Use of the Mental Capacity Act			
Correctly followed	1,453 (73.2%)	6,292 (64.9%)	**<0.001**
Not correctly followed	122 (6.1%)	644 (6.6%)	
Not known	411 (20.7%)	2,765 (28.5%)	
Total	1,986 (100.0%)	9,701 (100.0%)	

Appendix 3.14: *Quality of care for adults with Down syndrome and other adults with a learning disability, who died between 2021 and 2024, using focused reviews.*

Quality of care	Adults with Down syndrome	Other adults with a learning disability	*p-value*
Concerns identified*			
Yes	119 (25.1%)	889 (33.1%)	**<0.01**
No	339 (71.4%)	1,704 (63.4%)	
Not known	17 (3.6%)	96 (3.6%)	
Total	475 (100.0%)	2,689 (100.0%)	
Care package met the needs of the person			
Yes	372 (78.3%)	2,037 (75.8%)	0.227
No	103 (21.7%)	652 (24.2%)	
Total	475 (100.0%)	2,689 (100.0%)	
Reasonable adjustments made			
All reasonable adjustments provided	360 (75.8%)	1,957 (72.8%)	0.172
Reasonable adjustments should have been provided but were not	115 (24.2%)	732 (27.2%)	
Total	475 (100.0%)	2,689 (100.0%)	

*Sections are based on focused reviews and are included to maintain comparability with the LeDeR 2023 annual report.

Appendix 3.15: *Qualitative framework analysis for adults with Down syndrome who died between 2021 and 2024 using focused reviews.*

Delays in care

What

Recognition of cognitive and physical deterioration, late end-of-life and ReSPECT planning, and failures to reassess increasing care and placement needs as health declined particularly, dementia care.

- Dementia deterioration recognition
- End-of-life planning
- Care needs reassessment and placement

"The delay in diagnosing dementia meant there was no opportunity to consider medication that could have slowed the progression of his dementia"

"Spent over 6 months in a care setting that all agreed was inappropriate"

Where

Delays occurred across primary care, community, dementia, and hospital services, particularly in monitoring and ongoing management of deteriorating health needs.

- Community and primary care services
- Memory clinics and specialist dementia services
- Acute hospital and discharge planning services

"There was a delay in reassessing his care needs. There was a delay in diagnosing dementia due to a lack of early baseline assessments"

"Unsafe discharge"

When

Transitions between care settings and hospital admission where escalation, coordination, specialist involvement and reassesment of changing needs were often delayed.

- Progressive cognitive and physical deterioration
- Transition between care settings
- Admission to hospital

"Living in three different residential homes within space of two months"

"Delays considering the need for aids and adaptations, delays in moving to a provider who could appropriately meet his needs"

Gaps in care

What

Inconsistent monitoring and follow-up, fragmented coordination between services and failures to adapt care and support as health and care needs changed.

- Long-term condition monitoring and follow-up
- MDT coordination, and discharge planning
- Reasonable adjustments and reassessment

"No further follow up from the respiratory team occurred despite last clinic letter noting reviews to continue"

"There was no evidence of any reasonable adjustments that were attempted/provided"

Where

Gaps were identified across primary care, hospital and residential services where monitoring, preventative care, adapting to changing needs and continuity of care were inconsistent.

- Primary care
- Acute Hospital
- Residential care

"There was a lack of the person receiving annual epilepsy reviews"

"Shortage of available accommodation for people who need regular nursing support"

When

During the ongoing management of conditions, periods of increasing dependency and frailty, hospital admission and discharge and transitions between services, where follow-up and coordination of care was inconsistent.

- Ongoing management of conditions
- Hospital admission and discharge
- Transitions between services

"No End of Life Plan. This meant that the staffing and equipment could not be provided. This meant that she could not return home"

"Full investigation about repeated bouts of constipation did not take place"

Problems with organisational systems

What

Poor communication, inconsistent implementation of care processes and failure in the coordination of support when needs became more complex.

- Information sharing
- MCA, consent, best interest decision-making
- Referral pathways and follow-up care

"Assessment of capacity, best interests decision making and reasonable adjustments were not noted "

"The health care team involved in care and treatment were not invited to be involved in the instigation of the ReSPECT form"

Where

Poor communication between primary and secondary care and a lack of coordination between health and social care services.

- Between primary and secondary care
- Between health and social care services

"Adult Social Care were seemingly unaware of this need"

"There was no correspondence from the Acute Hospital Trust to the person's GP"

When

Organisations failed to coordinate care during admission and discharge from the hospital. Systems often failed to adapt to changing needs, particularly as dementia and physical needs progressed.

- Hospital admission and discharge
- Dementia and other health needs management
- Transitions between services

"A failure in sharing and acting on critical information raised by liaison nurse "

"had his annual health check, there was no reference to specific screening... and no mention of dementia...no updated or revised health action plan"

Diagnosis & treatment guidelines not met

What

Inconsistent monitoring, limited specialist review, and non-adherence to NICE guidance, reasonable adjustments, and anticipatory care planning.

- Inadequate monitoring and specialist follow-up
- Non-adherance to NICE guidance

"NICE guidance was not adhered to regarding the persons dementia, weight and epilepsy"

"Diagnosis was not referred to specialist service or given any treatment or management plan"

Where

Primary care, specialist services and community care services where monitoring, investigation and preventative care were often inconsistent.

- Primary care
- Specialist services
- Community care services

"The GP does not appear to have followed good practice in relation to pain assessment and management"

"The epilepsy pathway was not followed effectively"

When

During long-term management of complex health conditions, periods of deterioration end-of-life care and when needs changed.

- Changing needs reassessment
- Long term condition management
- End-of-life care

"Palliative care and end of life was not well implemented. Confusion regarding SLT guidance. Reassesment was not undertaken"

"Did not receive any direct physiotherapy treatment following her fracture and discharge from hospital"

Chapter 4

Appendix 4.1: *Demographics of autistic adults without a learning disability who died between 2021 and 2024, using notifications.*

Demographic	2021 – 2024
Sex registered at birth	
Female	97 (24.6%)
Male	242 (61.3%)
Not known	56 (14.2%)
Total	395 (100.0%)
Ethnic group	
Asian or Asian British	5 (1.3%)
Black African, Caribbean, or Black British	*
Mixed ethnic group	9 (2.3%)
Other ethnic group	*
Preferred not to say	75 (19.0%)
White	300 (75.9%)
Total	395 (100.0%)
Region	
London	34 (8.6%)
South West	45 (11.4%)
South East	68 (17.2%)
Midlands	86 (21.8%)
East of England	36 (9.1%)
North West	76 (19.2%)
North East and Yorkshire	50 (12.7%)
Total	395 (100.0%)

* Fewer than five cases

Appendix 4.2: *Demographics of autistic adults without a learning disability who died between 2021 and 2024, using focused reviews.*

Demographic	2021-2024
Sex registered at birth	
Male	208 (73.0%)
Female	67 (23.5%)
Not known	10 (3.5%)
Total	285 (100.0%)
Sexual orientation	
Heterosexual	97 (34.0%)
Other than heterosexual	36 (12.6%)
Not recorded	152 (53.3%)
Total	285 (100.0%)
Marital status	
Single	182 (63.9%)
Married/Civil Partner	33 (11.6%)
Divorced or separated	20 (7.0%)
Not Disclosed/Other	50 (17.5%)
Total	285 (100.0%)
Did the person have children?	
Yes	63 (22.1%)
No	166 (58.2%)
Unknown	56 (19.6%)
Total	285 (100.0%)
Employment	
Yes (paid or voluntary work)	23 (8.1%)
No	209 (73.3%)
Unknown	53 (18.6%)
Total	285 (100.0%)
Ethnic group	
Asian or Asian British	7 (2.5%)
Black, African, Caribbean or Black British	6 (2.1%)
Mixed ethnic group	*
Other ethnic group	*
They preferred not to say	18 (6.3%)
White	247 (86.7%)
Total	285 (100.0%)
Median age at diagnosis of autism	
Male	31.5
Female	31.0
Overall**	32.0
Total	226 (100.0%)

Index of Multiple Deprivation	
1 (most deprived areas)	45 (15.8%)
2	40 (14.0%)
3	37 (13.0%)
4	20 (7.0%)
5	25 (8.8%)
6	26 (9.1%)
7	32 (11.2%)
8	29 (10.2%)
9	18 (6.3%)
10 (least deprived areas)	13 (4.6%)
Total	285 (100.0%)

* Fewer than five cases
**Also included cases with unknown sex.

Appendix 4.3: *Most common grouped causes of death for autistic adults without a learning disability who died between 2021 and 2024, using focused reviews.*

Grouped underlying cause of death	2021-2024
Suicide, misadventure or accidental death**	94 (33.0%)
Diseases of the circulatory system	49 (17.2%)
Neoplasms	43 (15.1%)
Diseases of the digestive system	25 (8.8%)
Diseases of the nervous system	19 (6.7%)
Diseases of the respiratory system	17 (6.0%)
Endocrine and metabolic diseases	8 (2.8%)
Provisional assignment of new diseases***	7 (2.5%)
Mental and behavioural disorders****	7 (2.5%)
Symptoms, signs, and abnormal clinical findings	*
Other	7 (2.5%)
Not known	*
Total	285 (100.0%)

* Fewer than five cases

** Suicide, misadventure or accidental death is not an ICD-10 chapter. This category groups deaths due to intentional self-harm and accidental or unintentional external causes, which are recorded across ICD-10 external cause codes, rather than within a single ICD-10 disease chapter.

***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).

****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.

Appendix 4.4: *Circumstances of death for autistic adults without a learning disability who died between 2021 and 2024, using initial reviews.*

Circumstances of death	2021-2024
Was the Mental Capacity Act followed correctly?	
Correctly followed	103 (36.1%)
Not correctly followed	15 (5.3%)
Not known	167 (58.6%)
Total	285(100.0%)
DNACPR decision at death	
Yes	104 (36.5%)
No	181 (63.5%)
Total	285 (100.0%)
(If yes to above) Was the DNACPR documentation correctly completed and followed?	
Completed correctly and followed	69 (66.3%)
Completed correctly but not followed	*
Completed incorrectly but followed	5 (4.8%)
Neither correctly completed nor followed	*
Don't know	28 (26.9%)
Total	104 (100.0%)
Reported to a coroner	
Yes	161 (56.5%)
No	21 (7.4%)
Not known	103 (36.1%)
Total	285 (100.0%)
Was there a police investigation?	
Yes	87 (30.5%)
No	95 (33.3%)
Not known	103 (36.1%)
Total	285 (100.0%)
Safeguarding concerns	
Yes	27 (9.5%)
No	155 (54.4%)
Not known	103 (36.1%)
Total	285 (100.0%)

* Fewer than five cases

Appendix 4.5: *Circumstances of death for autistic adults without a learning disability who died between 2021 and 2024, using focused reviews.*

Circumstances of death	2021-2024
Reported to a coroner*	
Yes	187 (65.6%)
No	93 (32.6%)
Not known	5 (1.8%)
Total	285 (100.0%)
Was there a police investigation?*	
Yes	23 (8.1%)
No	262 (91.9%)
Total	285 (100.0%)
Safeguarding concerns*	
Yes	14 (4.9%)
No	271 (95.1%)
Total	285 (100.0%)
Serious incident review of the death	
Yes	50 (17.5%)
No	235 (82.5%)
Total	285 (100.0%)
Postmortem	
Yes	144 (50.5%)
No	141 (49.5%)
Total	285 (100.0%)

*Sections are based on focused reviews and are included to maintain comparability with the LeDeR 2023 annual report.

Appendix 4.6: *Physical and mental health comorbidities for autistic adults without a learning disability who died between 2021 and 2024, using focused reviews.*

Health condition	2021-2024
Physical health condition	
Cardiovascular conditions	82 (28.8%)
Respiratory conditions (including COVID-19)	73 (25.6%)
Smoker (yes or previous)	Yes=69 (24.2%), previous=32 (11.2%)
Impaired mobility	64 (22.5%)
Constipation	64 (22.5%)
Diabetes	60 (21.1%)
Sleep disorder	50 (17.5%)
Cancer	47 (16.5%)
Sensory impairment (vision or hearing problems)	46 (16.1%)
Skin conditions	41 (14.4%)
Epilepsy	36 (12.6%)
Endocrine conditions	32 (11.2%)
Renal conditions	29 (10.2%)
Swallowing issues	25 (8.8%)
Aspiration pneumonia	16 (5.6%)
Dental problems	14 (4.9%)
Dementia	11 (3.9%)
Parkinson's disease	*
Mental health condition	
Depression	153 (53.7%)
Anxiety	141 (49.5%)
Behaviour disorders	63 (22.1%)
History of suicide attempts	56 (19.6%)
History of self-harm	55 (19.3%)
Psychosis	46 (16.1%)
Eating disorder	17 (6.0%)
Bipolar disorder	15 (5.3%)
Total	285 (100.0%)

* Fewer than five cases

Appendix 4.7: *Mental health support offered for autistic adults without a learning disability by cause of death.*

Mental health support	Deaths by suicide*	Deaths due to all other causes
History of mental health medication**		
Anti-depressant prescription	38 (64.4%)	121 (53.5%)
Anti-psychotic prescription	21 (35.6%)	71 (31.4%)
Anti-anxiety prescription	31 (52.5%)	71 (31.4%)
Talking therapies offered		
Yes	43 (72.9%)	85 (37.6%)
No	6 (10.2%)	74 (32.7%)
Not known	10 (16.9%)	67 (29.6%)
Total	59 (100.0%)	226 (100.0%)

*ICD-10 codes X60-X84

**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.