

Learning from the lives and deaths of people with a learning disability and autistic people (LeDeR)

Annual Report
2024-2025



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Acknowledgements

The NHS South East London LeDeR programme would like to recognise and thank the individuals and organisations whose time, insight and commitment have supported the completion of LeDeR reviews, and the learning described in this 2024-2025 report.

- **Families, carers and those who knew the person well**

We are sincerely grateful to those who shared their experiences at a time of loss. Your perspectives have been essential in helping us understand the care your loved ones received and the impact of local health and social care services. This feedback continues to shape learning and drive improvement across the system.

- **The NHS South East London LeDeR Team**

With all reviews in south east London now being completed in-house, their dedication to the process ensures that each review reflects the person behind the process. Their thoughtful approach, expertise and continued commitment to person centred learning remain central to the strength of the LeDeR programme in south east London.

- **Local authorities and service providers across south east London**

For their cooperation and timely sharing of information that enabled reviews to be completed. Their engagement is vital to developing an accurate understanding of care pathways and identifying opportunities for learning.

- **Members of the LeDeR Focused Review Panel, LeDeR Strategic Group and Local Steering Groups**

For their oversight, challenge and support in translating review findings into meaningful system learning.

- **NHS South East London LeDeR Local Leads**

For their leadership, coordination and ongoing contribution to the delivery of the programme at place level.

- **NHS England Regional and National LeDeR team**

For their guidance and continued support of the NHS South East London LeDeR programme.

Introduction

The six boroughs that make up south east London (Bexley, Bromley, Greenwich, Lambeth, Lewisham and Southwark) have a combined population of more than two million residents. From April 2024-March 2025, NHS South East London Integrated Care System (ICS) was responsible for providing health and care services to 10,802 people registered with a GP in south east London who were recorded as having a learning disability, and to 30,270 people with a formal diagnosis of autism.

Figure 1.0 **The south east London learning disability population.**
Data source: NHS South East London Learning Disability and Autism Dashboard.

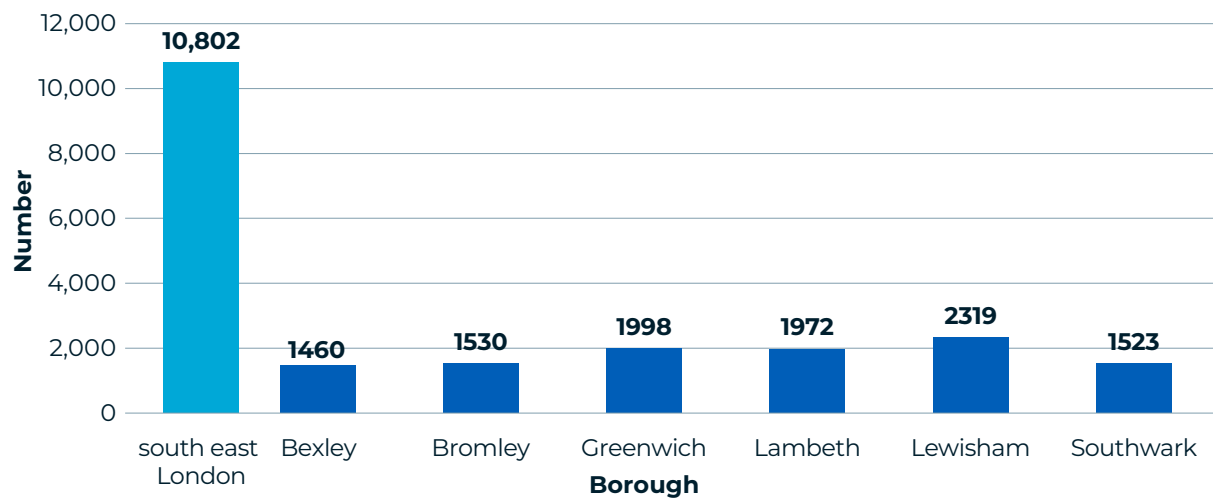
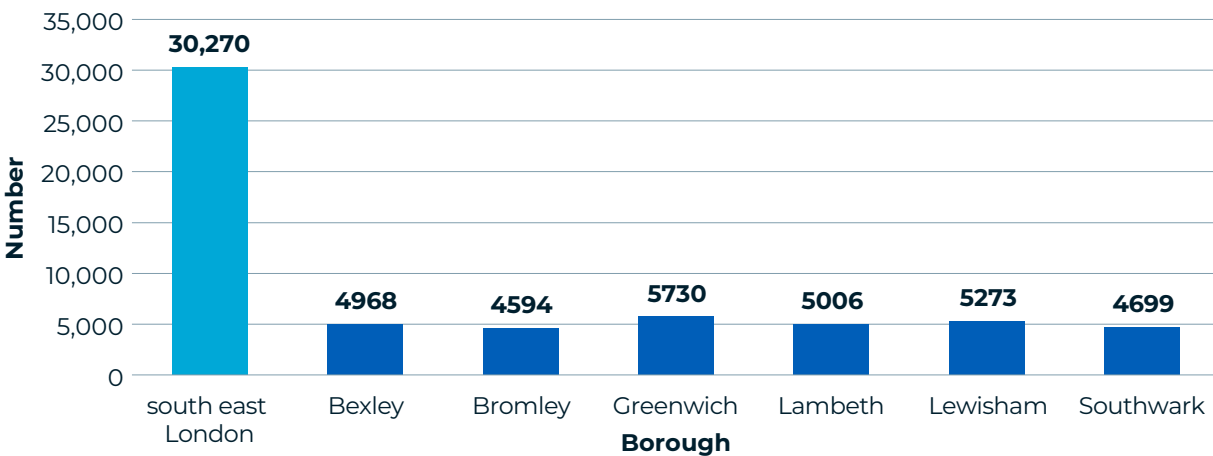


Figure 1.1 **The south east London autism population.**
Data source: NHS South East London Learning Disability and Autism Dashboard.



Foreword

People with a learning disability and autistic people continue to experience unacceptable health inequalities, including poorer outcomes and reduced life expectancy. The Learning from Lives and Deaths of People with a Learning Disability and Autistic People (LeDeR) programme is a vital component of the NHS South East London Integrated Care System (ICS) approach to addressing these inequalities and delivering the ambitions set out in the Joint Forward Plan.

This Annual Report for April 2024 to March 2025 brings together learning from LeDeR reviews across south east London and highlights key themes that align directly with our system priorities. These include improving the quality and safety of inpatient and community services, and ensuring people are supported to live well in their local communities wherever possible. The report reinforces the importance of timely access to care, adherence to the Mental Capacity Act and Deprivation of Liberty Safeguards, consistent reasonable adjustments, effective care coordination, and strong system oversight. The report also highlights an increase in adult social care packages that effectively met the needs of adults with learning disability and autistic people, compared with findings from the previous year.

We have made significant progress towards embedding learning and positive practice from LeDeR into service improvement projects, including cancer projects, promoting completion of annual health checks and ongoing roll out of the Oliver McGowan mandatory training across south east London.

We are grateful to families, carers, reviewers, clinicians and partners who contribute to the LeDeR process. Their involvement ensures that learning is grounded in lived experience and used to drive meaningful improvement.

As system leaders, we are clear that learning must lead to action. The findings and priorities in this report will inform local and system wide improvement plans, strengthen accountability, and support delivery of the Joint Forward Plan ambition to reduce health inequalities and improve outcomes for people with a learning disability and autistic people across south east London.

Diane Jones

Interim Chief Nursing Officer
NHS South East London Integrated
Care Board

Chapter one

Notifications

South East London LeDeR Demographics

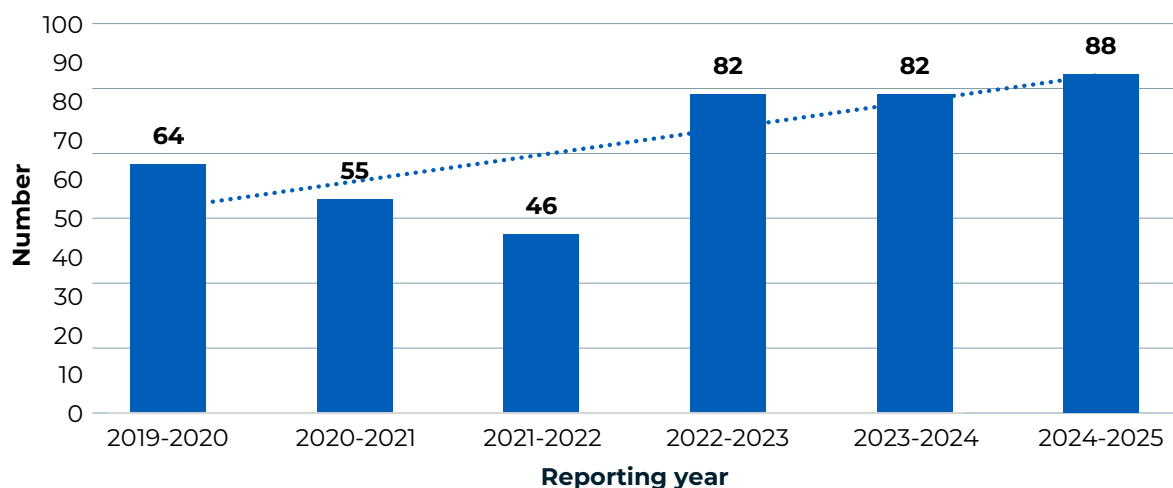
Introduction to the chapter, what it includes:

In this chapter, information collected from the LeDeR notification form is summarised. The analysis includes the total number of notifications received each month, information about the notifier's relationship to the person who died, basic demographic information about the person who died, and their age at death.

Number of LeDeR notifications

A total of 88 LeDeR notifications were received by NHS South East London ICB between April 2024 and March 2025, this is an increase compared to previous years. Figure 1.2 shows the number of notifications received each reporting year since 2019, representing a total of 417 deaths. The number of notifications decreased between 2019-2020 (64) and 2021-2022 (46) before rising sharply to 82 in 2022-2023. This higher level of reporting was maintained in 2023-2024, with a further increase observed in 2024-2025. Overall, the data shows a sustained upward trend in the number of deaths being reported through LeDeR. This reflects an increase in awareness of the LeDeR programme across south east London.

Figure 1.2 **Reported notifications by year since 2019**



Number of notifications per borough

A total of 88 LeDeR notifications were received across the six south east London boroughs between April 2024 and March 2025. The largest number of notifications were from Lewisham 19 (22.0%), followed by Greenwich 18 (20.0%), Bromley 17 (19.0%), Bexley 12 (14.0%) with Lambeth and Southwark both having 11 (12.5%).

Table 1.0 **Number of LeDeR Notifications per borough since 2019**

Borough	2019-20	2020-21	2021-22	2022-23	2023-24	2024-25	Total	% of all SEL* notifications
Bexley	8	10	4	15	15	12	64	16.0%
Bromley	11	13	5	13	12	17	71	18.0%
Greenwich	10	9	12	13	19	18	81	21.0%
Lambeth	10	7	7	17	16	11	68	18.0%
Lewisham	16	10	9	12	9	19	75	19.0%
Southwark	9	6	9	12	11	11	58	15.0%

* south east London

Notifications by month

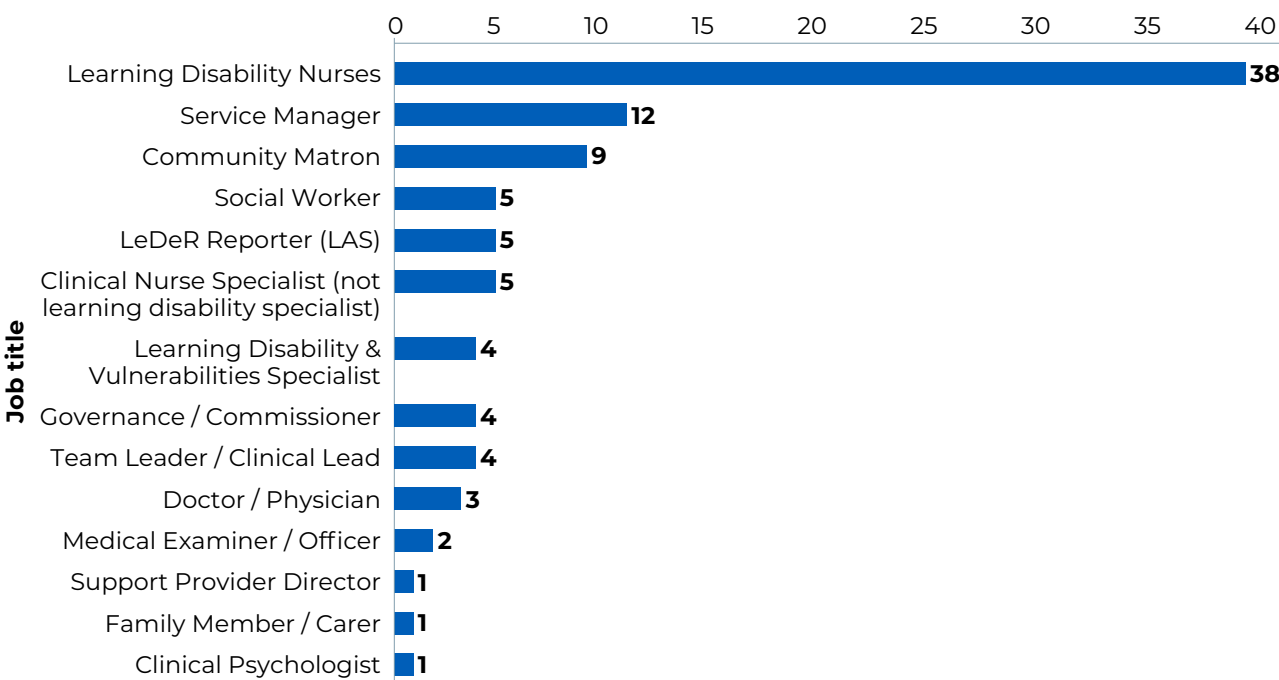
Figure 1.3 **Notifications by Month (2024-25)**



Who notified to LeDeR

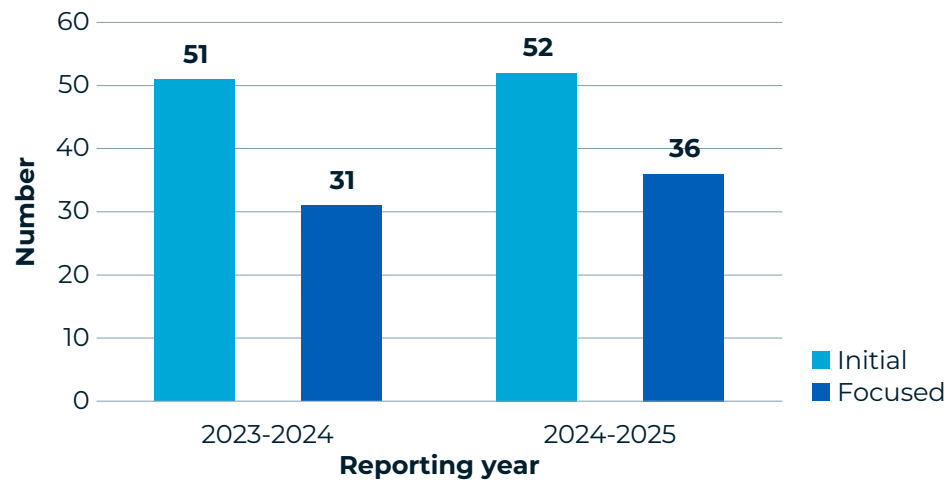
Most notifications were submitted by professionals working in learning disability nursing roles, with 38 reports made by Learning Disability Nurses, Clinical Nurse Specialists, or Liaison Nurses. A further 12 notifications were received from Adult Learning Disability Managers or Service Managers, and nine from Community Matrons. Smaller numbers of notifications came from social workers, LeDeR reporters within the London Ambulance Service, and other clinical nurse specialists, including those in palliative care and dementia care. Additional notifications were submitted by Learning Disability and Vulnerabilities Specialists, governance or commissioning staff, and team leaders. A small number of notifications were made by doctors, medical examiners, and non-clinical contributors such as support providers, family members, or carers. It is important to note that some duplicate notifications are received, meaning these figures may not fully reflect the exact distribution of notifier roles.

Figure 1.4 **Role of notifier for LeDeR notifications in south east London, 2024-2025**



Type of review

Figure 1.5 **Number of LeDeR initial and focused reviews received in 2023-2024 and 2024-2025**



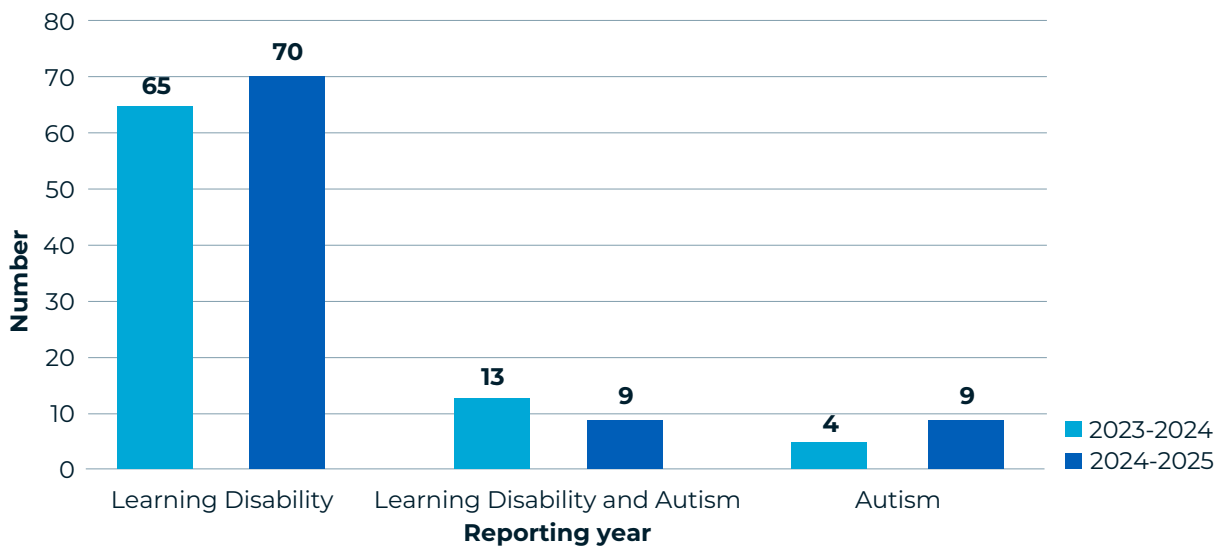
Type of patient

Every adult (aged 18 and over) with a learning disability and/or a diagnosis of autism is eligible for a LeDeR review following their death. At the time of notification, the notifier selects the type of patient:

- person with a learning disability,
- person with both a learning disability and autism, or
- autistic person without a learning disability

Of the 88 notifications received in between April 2024 and March 2025, 70 notifications were for people with a learning disability, nine for people with both a learning disability and autism, and nine for autistic people without a learning disability. Compared to 2023–2024, this represents a small increase in notifications for people with a learning disability and for autistic people.

Figure 1.6 **Type of patient**



Age at death

Across all boroughs, most notifications were related to people aged 56–65 years (23.9%) and 66–75 years (21.6%), together accounting for 45.5% of all deaths. Smaller proportions were recorded for those aged 46–55 years (18.2%) and 76–85 years (15.9%), while 18.1% of notifications involved people under 45 years. The smallest proportion was among those aged 86 years and over (2.3%).

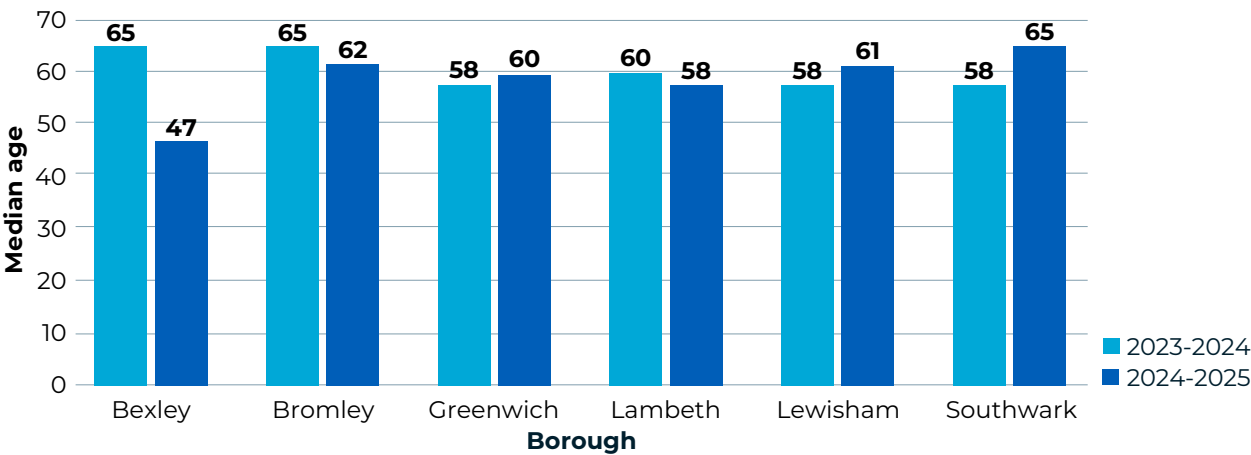
Table 1.1 **Notifications by borough and age group (2024-2025)**

Borough	18-25	26-35	36-45	46-55	56-65	66-75	76-85	86+
Bexley	16.7%	16.7%	25.0%	8.3%	16.7%	8.3%	8.3%	0.0%
Bromley	5.9%	5.9%	0.0%	11.8%	35.3%	23.5%	11.8%	5.9%
Greenwich	5.6%	0.0%	5.6%	27.8%	22.2%	22.2%	16.7%	0.0%
Lambeth	9.1%	9.1%	9.1%	0.0%	27.3%	36.4%	9.1%	0.0%
Lewisham	5.3%	0.0%	5.3%	31.6%	21.1%	10.5%	21.1%	5.3%
Southwark	0.0%	0.0%	0.0%	18.2%	18.2%	36.4%	27.3%	0.0%

Median age at death

From the 88 LeDeR notifications received, the median age of death for people with a learning disability and autistic people in south east London was 60 for males and 59 for females. Figure 1.7 shows the median age at death for each borough. Bexley had the lowest median age of notifications received across the six south east London boroughs, reflecting a greater number of notifications involving people under 35 years of age.

Figure 1.7 **Median age at death for the notifications received in each borough between April 2023 and March 2025**



Gender

In 2024–2025, males accounted for 59.0% of LeDeR notifications and females for 41.0%. This reflects a 6.0% increase in the proportion of female notifications compared with 2023–2024, when females accounted for 35.0% of notifications. While the gender balance has varied year to year, males have consistently represented the majority of notified deaths.

Figure 1.8 **Gender**

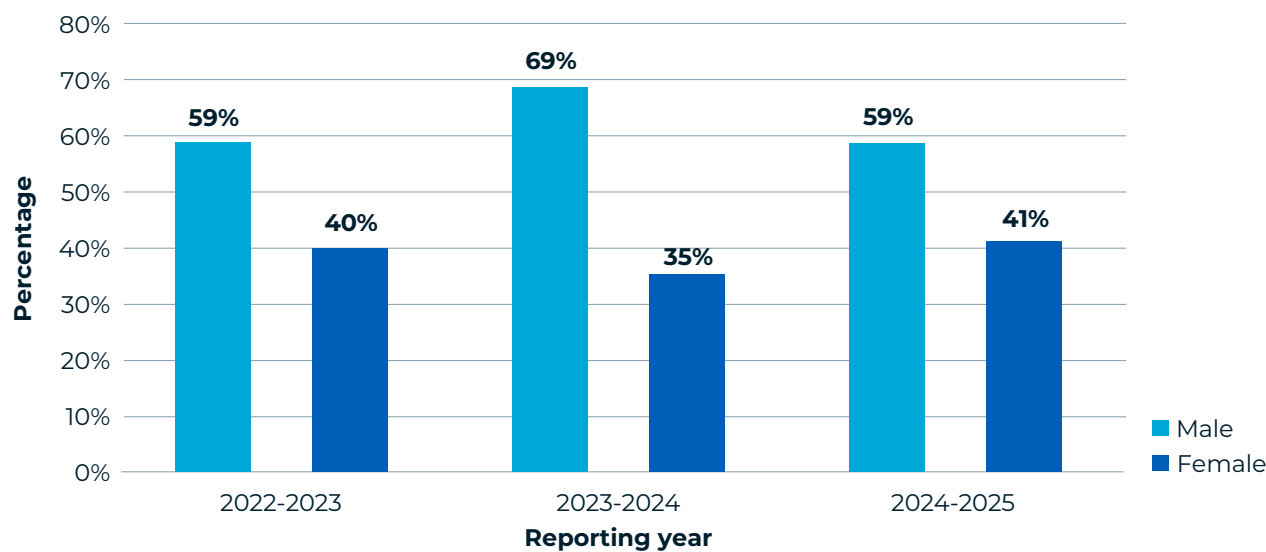


Table 1.2 shows the distribution of male and female notifications across each age group for 2024–2025. Patterns vary across the life course, with some age groups showing similar numbers of male and female deaths, while others show clearer differences. For example, the 46–55 and 56–65 age groups have higher numbers of male notifications, whereas the 76–85 group has more female notifications. Younger (18–25) and oldest (86+) groups show an equal split between genders.

Table 1.2 **Gender Breakdown by Age Group (2024–2025)**

Age group	Female (%)	Male (%)
18-25	50.0%	50.0%
26-35	100%	0.0%
36-45	50.0%	50.0%
46-55	25.0%	75.0%
56-65	33.3%	66.7%
66-76	31.6%	68.4%
76-85	57.1%	42.9%
86+	50.0%	50.0%

Table 1.3 **Gender comparison: south east London LeDeR notifications and learning disability population (April 2024 to March 2025)**

Data Source: NHS South East London LeDeR Programme; NHS South East London Learning Disability and Autism Dashboard; ONS Deaths Registered in England & Wales, 2024.

Dataset	Female (n)	Female (%)	Male (n)	Male (%)	Total (n)
Notifications received for people with a learning disability April 2024 to March 2025.	35	44.3%	44	55.7%	79
South east London learning disability population (all six boroughs combined)	4,217	39.0%	6,585	61.0%	10,802
General population deaths (England & Wales, 2024)	278,887	49.0%	289,726	51.0%	568,613

Table 1.3 compares the gender breakdown of LeDeR notifications with that of both the south east London learning disability population and the general population. The proportion of LeDeR notifications relating to males (55.7%) is lower than would be expected based on the proportion of males in the learning disability population across south east London (61.0%). As there were very few notifications for autistic people without a learning disability, a similar comparison could not be made for this group.



Ethnicity

In 2024–2025, the majority of notifications across south east London related to people identified as White (76.0%). Notifications for Black, African, Caribbean or Black British individuals accounted for 11.0%, while smaller proportions were reported for those of Mixed or Multiple ethnic groups (5.0%), Asian or Asian British backgrounds (2.0%), and Other ethnic groups (3.0%). Ethnicity was unknown or not stated in 1.0% of notifications.

Table 1.4 **Ethnicity of LeDeR Notifications Received per Borough (2024–2025)**

Borough	White	Black, African, Caribbean or Black British	Asian or Asian British	Mixed or Multiple Ethnic Group	Other Ethnic Group	Unknown / Preferred not to say
Bexley	90.0%	0.0%	0.0%	0.0%	10.0%	0.0%
Bromley	100%	0.0%	0.0%	0.0%	0.0%	0.0%
Greenwich	65.0%	18.0%	12.0%	12.0%	0.0%	0.0%
Lambeth	64.0%	0.0%	9.0%	9.0%	0.0%	0.0%
Lewisham	61.0%	28.0%	0.0%	6.0%	0.0%	6.0%
Southwark	71.0%	12.0%	0.0%	0.0%	6.0%	12.0%
Total (south east London)	76.0%	11.0%	2.0%	5.0%	3.0%	1.0%

A comparison of LeDeR notifications with the ethnic profile of the local learning disability population shows that White individuals are over-represented in notifications (76% vs 53.7% of the learning disability population), while Black, African, Caribbean or Black British individuals are under-represented (11.0% of notifications vs 26.3% of the learning disability population). Similar under-representation is seen for Asian, Mixed and Other ethnic groups across south east London. These patterns are also evident at borough level, where several areas with diverse learning disability populations show a higher proportion of White notifications than would be expected from local prevalence. This suggests the need for further investigation to understand potential barriers to equitable access, identification, notification and participation in the LeDeR process.

Table 1.5 **Ethnicity Profile of the Learning Disability Population by Borough**
2024-2025 (NHS South East London Learning Disability and Autism Dashboard)

Borough	White	Black, African, Caribbean or Black British	Asian or Asian British	Mixed or Multiple Ethnic Group	Other Ethnic Group	Unknown / Preferred not to say
Bexley	72.2%	20.8%	6.0%	6.3%	1.5%	3.2%
Bromley	76.7%	7.4%	4.7%	4.1%	2.0%	5.1%
Greenwich	59.4%	20.5%	9.1%	4.3%	2.9%	3.8%
Lambeth	35.19%	40.5%	5.6%	9.0%	4.1%	5.8%
Lewisham	44.5%	33.2%	4.8%	6.6%	3.7%	7.1%
Southwark	43.6%	38.2%	5.3%	5.9%	5.0%	2.0%
Total (south east London)	53.7%	26.3%	5.9%	6.1%	3.3%	4.7%



Chapter two

Completed LeDeR Reviews

Introduction to the chapter, what it includes:

This chapter includes a summary of the information found in the LeDeR reviews completed between April 2024 and March 2025.

Please note: throughout this chapter, the asterisk ** symbol is used to indicate numbers fewer than five.

Number of reviews completed

Between April 2024 and March 2025, the NHS South East London LeDeR team completed 82 LeDeR reviews, a 34.0% increase from the previous year. This significant increase in review completion observed in 2024/2025 is because of two contributory factors;

- Funding was provided to increase the staff capacity of the NHS South East London LeDeR team with a full-time fixed term Reviewer role. This role was initially funded for 12 months but later increased to 15 months.
- NHS South East London commissioned an external agency to complete LeDeR reviews for a period. This helped to address the backlog of reviews that had accumulated over time.

A breakdown of reviews by initial and focused is shown in table 1.6.

Note: All focused reviews start with an initial review. Figure 1.9 shows the number of reviews completed each month between April 2024 and March 2025.

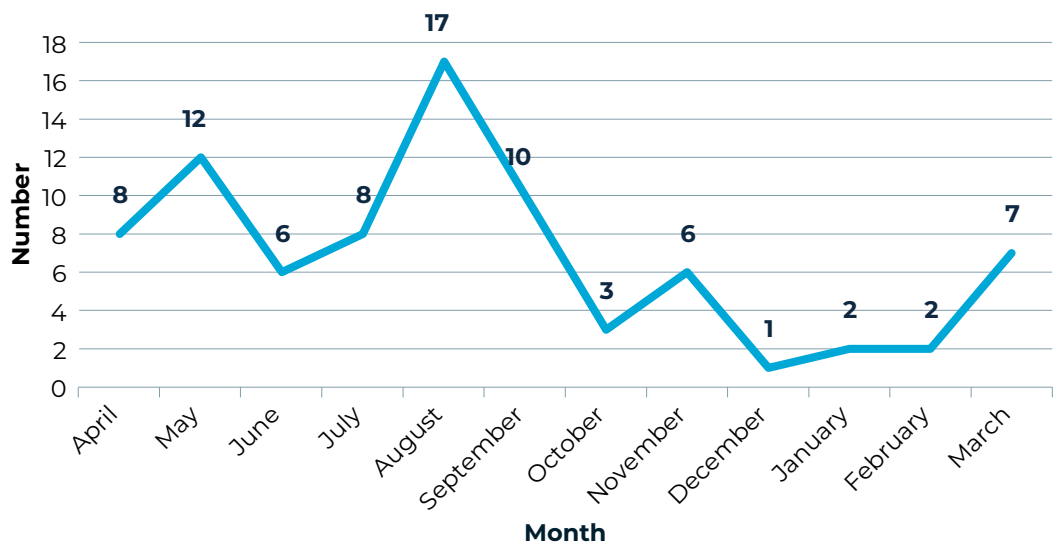
Table 1.6 **Number of initial and focused LeDeR reviews completed between April 2023 and March 2025**

Number of reviews completed	2023-2024 Number (%)	2024-2025 Number (%)
Initial	30 (56.0%)	40 (49.0%)
Focused	24 (44.0%)	42 (51.0%)
Total	54 (100%)	82 (100%)

Focused reviews

For some reviews, the initial review will be converted to a more comprehensive focused review, which looks even more closely at the person’s life and circumstances of their death. Focused reviews require the reviewer to answer additional questions in relation to the person’s social care package, delays in care, organisational and systemic problems, adherence to guidance around diagnosis and treatment, and gaps in care. Once completed, focused reviews are then presented at the NHS South East London Focused Review Panel. At this governance group, members of the group will discuss identified areas of good practice, areas of concern, wider areas of learning and agree actions that can be implemented to improve care delivery for people with a learning disability and autistic people.

Figure 1.9 **The number of completed reviews by month from April 2024 to March 2025**



Type of reviews completed

Like in previous reporting years, we continue to complete higher numbers of learning disability only reviews and a smaller number of autism only reviews.

Table 1.7 **Type of LeDeR reviews completed between April 2023 and March 2025**

Type of review	2023-2024 Number (%)	2024-2025 Number (%)
Learning Disability	45 (83.0%)	65 (79.0%)
Learning Disability and Autism	7 (13.0%)	14 (17.0%)
Autism	** (4.0%)	** (4.0%)
Total	54 (100%)	82 (100%)

Level of learning disability

Table 1.8 shows that review activity increased across all recorded levels of learning disability between April 2023 to March 2024 and April 2024 to March 2025, with the largest increase observed among people with a severe learning disability. The number of completed reviews for people with mild, moderate and severe learning disabilities all increased during the reporting period, suggesting improved review completion across the pathway. The proportion of cases where the level of learning disability was unknown or not recorded remained stable. While the number of people with a profound learning disability remains fewer than five in both reporting periods, a small increase was observed and will continue to be monitored alongside future trends.

Figure 2.0 suggests that the profile of learning disability severity varies by age at death. Severe learning disability represents a larger share of reviews among younger age groups, particularly those aged 18–24 and 25–49, while mild and moderate learning disability account for a greater proportion of reviews in the older age groups. Profound learning disability and unknown/not recorded categories remain small in number, although the continued presence of unknown/not recorded data reinforces the need to improve recording quality. Due to small numbers in some categories, findings should be interpreted with caution and monitored over time.

Table 1.8 **Level of learning disability recorded for reviews completed between April 2023 and March 2025**

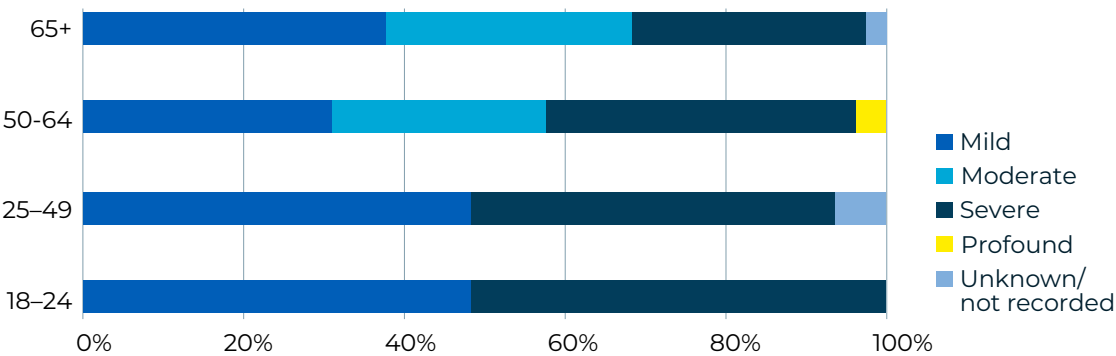
Level of learning disability	2023-2024 Number	2024-2025 Number
Mild	23	30
Moderate	13	19
Severe	11	27
Profound	**	**
Unknown/not recorded	**	**



Table 1.9 **Level of learning disability and age group at death for reviews completed April 2024-March 2025**

Age Group	Mild Number	Moderate Number	Severe Number	Profound Number	Unknown/ not recorded Number
18-24	**	0	**	0	0
25-49	7	0	6	0	**
50-64	8	7	10	**	0
65+	14	12	10	0	**

Figure 2.0 **Level of learning disability and age group at death for reviews completed April 2024-March 2025**



Autism only reviews

As with previous years, the NHS South East London LeDeR team has continued to receive very small numbers of notifications for autistic adults who do not have a co-occurring learning disability. In 2024-2025, three focused reviews were completed for autistic adults, representing only a slight increase from the previous year. Due to the small number of cases, and to maintain full confidentiality, detailed findings from these reviews have not been included in this report. We hope that in our next annual report 2025-2026, we will have more data to share on autism reviews completed since the addition of autism reviews to LeDeR in 2021.



Place of death

As in previous years, we continue to see the majority of deaths occurring in hospital. Of the 82 reviews completed, over half died in hospital (56.0%). 38.0% died in their usual place of residence, and a small number of reviews identified people that had died in a hospice or place of residence categorised as 'other'. Unfortunately, the records available for LeDeR reviews do not consistently document an individual's preferred place of death. As a result, this information could not be included within this report.

Table 2.0 Place of death for adults with a learning disability and or autistic people for whom a LeDeR review was completed between April 2023 to March 2025

Place of death	2023-2024 %	2024-2025 %
Hospital	50.0%	56.0%
Usual Place of Residence	35.0%	38.0%
Hospice	9.0%	**
Mental Health Unit	**	0.0%
Other	**	**

Table 2.1 Breakdown of hospital deaths for adults with a learning disability and autistic people for whom a LeDeR review was completed between April 2023 and March 2025

Hospital	2023-2024 (%)	2024-2025(%)
Darent Valley Hospital	4.0%	4.0%
Guys and St Thomas' Hospital	11.0%	17.0%
Kings College Hospital	30.0%	20.0%
Lewisham Hospital	7.0%	11.0%
Princess Royal Hospital	15.0%	9.0%
Queen Elizabeth Hospital	22.0%	35.0%
St Georges Hospital	7.0%	2.0%
Out of Borough Hospital	4.0%	2.0%

Hospital deaths reviewed through LeDeR were distributed across several acute hospital sites, with notable variation between 2023-2024 and 2024-2025. Queen Elizabeth Hospital accounted for the largest proportion of hospital deaths in 2024/25 (35.0%), representing a substantial increase from 22.0% in the previous year. In contrast, King's College Hospital remained a significant location of death but declined from 30.0% to 20.0% over the same period. Increases were also observed at Guy's and St Thomas' Hospital (11.0% to 17.0%) and Lewisham Hospital (7.0% to 11.0%), while Princess Royal Hospital, St George's Hospital and out-of-borough hospitals accounted for a smaller proportion of deaths than in the previous year.

These changes should be interpreted with caution, as the figures reflect the distribution of LeDeR reviews completed during the reporting period rather than a measure of hospital performance or quality of care. Variation is likely to be influenced by factors such as local population need, hospital catchment areas, patterns of service utilisation, and normal year-to-year fluctuation in relatively small numbers. Nevertheless, monitoring deaths by hospital of death remains important in identifying where learning from reviews may be concentrated and where engagement with providers can support quality improvement, implementation of reasonable adjustments, and the reduction of health inequalities for people with a learning disability and autistic people across south east London.



Deaths reported to a coroner

Certain deaths are reported to the coroner, these can include deaths that were unnatural, sudden or of an unknown cause. Deaths that also occur in custody such as deaths in prison, police custody and under the Mental Health Act would also be reported to the coroner. Of the 82 LeDeR reviews completed between April 2024 and March 2025 29.0% (24) were reported to the coroner.

Causes of death

On a UK death certificate, section 1a records the disease or condition that immediately caused death, with subsequent lines (1b, 1c) detailing the underlying causes leading back to the initiating event, and part 2 lists any other significant conditions that contributed but were not in the direct causal sequence, like chronic illnesses. The most common causes of death for adults with a learning disability and autistic people and who had a LeDeR review completed in 2024-2025 were: pneumonia (20.0%), cancer (12.0%) and heart disease (10.0%). Like 2023-2024 pneumonia continues to be the most common cause of death. The pneumonia-related deaths included a range of presentations, most commonly aspiration pneumonia and bronchopneumonia, which each accounted for 29.2% of the pneumonia deaths. Other types of pneumonia, including community-acquired pneumonia, hospital-acquired pneumonia and Covid-19 pneumonitis accounted for the remaining 41.6% of pneumonia deaths.

The finding that pneumonia continues to be the most common cause of death amongst completed LeDeR reviews highlights the importance of preventative measures such as the pneumococcal vaccination. Although the pneumococcal vaccine does not help protect against all causes of pneumonia, for example aspiration pneumonia and hospital-acquired pneumonia, ensuring that eligible individuals receive the pneumococcal vaccine may help reduce the risk of severe pneumococcal infection and its associated complications, particularly among people at increased risk of respiratory illness.

Note the data below has been taken from 1a of the death certificate.

Table 2.2 **Most common causes of death for adults with a learning disability and autistic people for whom a LeDeR review was completed between April 2023 and March 2025**

Rank	2023-2024 Number (%)	2024-2025 Number (%)
1st	Pneumonia 17 (31.0%)	Pneumonia 24 (20.0%)
2nd	Cancer 8 (15.0%)	Cancer 10 (12.0%)
3rd	Sepsis 5 (9.0%)	Heart Disease 8 (10.0%)

Cause of death by gender

Table 2.3 shows the most common underlying cause of death by gender. In 2024-2025 Pneumonia continued to be ranked as the most common underlying cause of death for both male and female. In 2024-2025 whilst cancer remained in 2nd position for males it fell into third position for females. Cardiac disease remained in 3rd position for males however in 2024-2025 this was joint with sepsis.

Table 2.3 **Most common underlying causes of death for those that had a LeDeR review completed between April 2024 and March 2025, by gender**

Rank	Male 2023-2024	Male 2024-2025	Female 2023-2024	Female 2024-2025
1st	Pneumonia	Pneumonia	Pneumonia	Pneumonia
2nd	Cancer	Cancer	Cancer	Cardiac Disease
3rd	Cardiac Disease Respiratory Illnesses	Cardiac Disease Sepsis	Sepsis	Cancer

Cause of death by borough

Cause of death by borough:

Table 2.4 shows that the main cause of death remained the same in the boroughs of Bromley, Greenwich and Lambeth, whilst Bexley, Lewisham and Southwark all saw a change. Pneumonia remains the most common cause of death across south east London.

Table 2.4 **Main cause of death recorded for each borough for adults with a learning disability and autistic people for whom a LeDeR review was completed between April 2023 and March 2025**

Borough	2023-2024	2024-2025
Bexley	Pneumonia	Heart Disease
Bromley	Pneumonia	Pneumonia
Greenwich	Pneumonia	Pneumonia
Lambeth	Pneumonia	Pneumonia
Lewisham	Respiratory illnesses	Pneumonia and Cancer*
Southwark	Cancer	Pneumonia

*Joint cause of death

Cause of death by age group

Table 2.5 shows the most common causes of death by age group. In 2024-2025 the 18-24 age group was the only group to not report any pneumonia deaths, however the number of people within this group was small so this finding should be interpreted with caution.

Table 2.5 **Most common causes of death for each age group for adults with a learning disability and autistic people for whom a LeDeR review was completed between April 2023 and March 2025**

Age Group	Most common causes of death 2023-2024	Most common causes of death 2024-2025
18-24	Respiratory conditions including Pneumonia	Gastrointestinal haemorrhage Cardiac disease
25-49	Pneumonia Sudden unexpected death in Epilepsy (SUDEP)	Pneumonia Cardiac disease
50-64	Pneumonia Cancer	Pneumonia, Sepsis and Dementia
65+	Pneumonia, Sepsis and Cancer	Pneumonia, Cardiac disease and Cancer



Deaths with DNACPR decisions

Of the 82 reviews completed between April 2024 and March 2025, 46 people had a Do Not Attempt Cardiopulmonary resuscitation (DNACPR) decision in place at the time of their death. For 34 people the reviewer saw documented evidence to show that a conversation had taken place with the person, or those important to them, to explain Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) and ask about their preferences and wishes relating to this. However, this discussion does not always take place as five reviews recorded that no discussion had occurred about a DNACPR, and for seven reviews it was unknown if a conversation had taken place as records available did not include this information.

Table 2.6 **Number of deaths where a DNACPR decision was in place for adults with a learning disability and autistic people for whom a LeDeR review was completed between April 2023 and March 2025.**

DNACPR decision at death	2023-2024 Number (%)	2024-2025 Number (%)
Yes	23 (43.0%)	46 (56.0%)
No	31 (57.0%)	36 (44.0%)
Total	54 (100%)	82 (100%)



End of life care plan

As well as having common palliative care needs such as pain management, spiritual, and emotional needs, people with a learning disability and autistic people often have additional needs in end-of-life care. It is important that services understand and consider these needs when providing end-of-life care as this can help to improve a person’s quality of life. In the reviews completed in 2024-2025, 34 reviews indicated that an end-of-life care plan had been put in place, with the highest number seen in those who had a severe learning disability. Whilst the reviewers were able to identify how many reviews had an end-of-life care plan in place they were unable to comment on the quality or content of the plan as this was often not seen as part of the review process.

Of the 34 people who had an end-of-life care plan, 29 had a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) in place. For 21 of these reviews, the reviewer saw evidence that a conversation had taken place with the person, or those important to them, to explain the DNACPR and ask about their preferences and wishes. For the remaining eight reviews, factors such as the person not having a closest living relative or someone who knew them well or it not being recorded on the DNACPR meant the reviewer was unable to determine if a conversation took place.

Table 2.7 **Level of learning disability for those that had an end-of-life care plan in place**

Level of learning disability	2023-2025 Number (%)	2024-2025 Number (%)
Mild	10 (42.0%)	9 (27.0%)
Moderate	6 (25.0%)	11 (32.0%)
Severe	6 (25.0%)	12 (35.0%)
Profound	** (4.0%)	** (3.0%)
Autistic adult without a learning disability	** (4.0%)	** (3.0%)
Total	24 (100%)	34 (100%)

Learning disability register

Of the 82 reviews completed in 2024-2025, 79 were of people with a learning disability. Of these 79 people, 76 (92.0%) were on the learning disability register.

Learning disability annual health check

Of the 79 LeDeR reviews completed for people with a learning disability, 56 people (71.0%) were recorded as having an annual health check and 23 people (29.0%) were recorded as not having an annual health check. Reasons for the recording that an annual health check did not take place included:

- The reviewer saw no evidence of an annual health check in the records
- The person was invited but did not attend
- The annual health check did not take place in the 12 months before death
- The person was either too unwell or admitted to hospital

Table 2.8 **The percentage of learning disability health checks completed in each south east London borough for those aged 14 and above between April 2023 and March 2025**

Data Source: Learning Disabilities Health Check Scheme – NHS England Digital.

Borough	2023-2024 Learning Disability Population	2023-2024 % with Annual Health Check	2024-2025 Learning Disability Population	2024-2025 % with Annual Health Check
Bexley	1184	76.8%	1233	79.2%
Bromley	1216	83.6%	1247	87.2%
Greenwich	1592	79.8%	1679	83.4%
Lambeth	1639	84.4%	1712	82.5%
Lewisham	1920	78.1%	1981	76.3%
Southwark	1243	82.4%	1288	83.4%

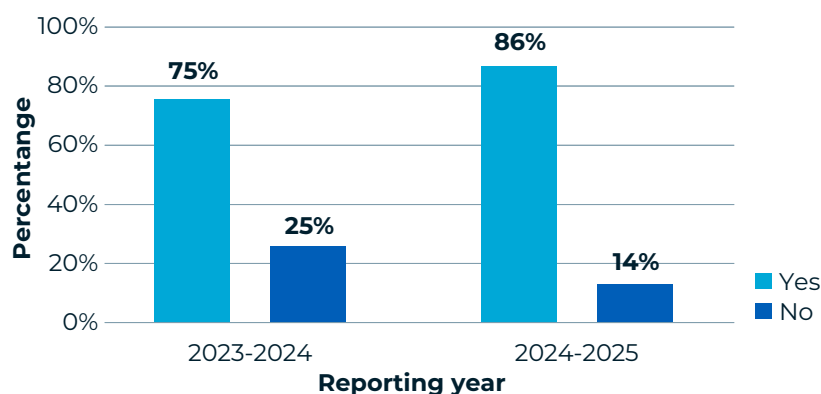
Social care package

Of the 42 focused reviews completed between 2024-2025, reviewers were asked to indicate whether the social care package appeared to have met the needs of the person who died. 36 (86.0%) of adults with a learning disability and autistic people who had a focused LeDeR review completed in 2024-2025 were deemed by the reviewer to have had a care package that met their needs. However, in six (14.0%) of the 2024-2025 focused reviews, reviewers noted that the social care package did not meet the needs of the person who died.

Some of the reasons identified in these reviews for the care package not meeting the needs of person included:

- The care provider being unable to meet the person's needs due to non-compliance with the care plan
- A lack of awareness and understanding of the requirements of people with a learning disability by care staff
- Eating and drinking guidelines not being followed by care providers
- Hygiene needs not being met
- The person's care needs not being formally assessed by adult social care

Figure 2.1 **Percentage of people whose care package met their needs for adults with a learning disability and autistic people who received a LeDeR review between April 2023 and March 2025**



Quality of care

As part of a focused review, reviewers are asked to grade the quality of care the person received from a 6-point scale. This is based on the person's overall experience of the care received in services accessed. The grading scale is shown below in table 2.9. Of the 42 focused reviews completed between April 2024 and March 2025, the highest proportion, 38.1%, were graded a 3. This grading indicates that care fell short of good practice but did not contribute to the cause of death. 21.4% of completed focused reviews were graded below a 3 indicating that care either fell short of good practice and significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death, or that the standard of care did contribute to the cause of death. 40.5% of completed focused reviews were graded as 4 and 5 combined indicating satisfactory or good care, but no reviews were graded as 6 which indicates excellent care.

Table 2.9 **Grading of quality of care**

1	Care fell far short of expected good practice, and this contributed to the cause of death
2	Care fell short of expected good practice, and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death
3	Care fell short of expected good practice, and this did impact on the person's wellbeing but did not contribute to the cause of death
4	This was satisfactory care (it fell short of expected good practice in some areas, but this did not significantly impact on the person's wellbeing)
5	This was good care (it met expected good practice)
6	This was excellent care (it exceeded expected good practice)



Responsiveness of Integrated Care System services

In addition to grading the quality of care, reviewers are also asked to grade the effectiveness of Integrated Care System services in the time leading up to the person's death and whether the person got the right support at the right time and in the right place. For the purpose of this report, Services refers to the health and social care services planned, delivered and coordinated to ensure that people living within south east London receive seamless care to meet their needs. The grading scale is shown below in table 3.0.

Of the 42 focused reviews completed between April 2024 and March 2025, the highest proportion, 40.5%, were graded a 3. This grading indicates that the responsiveness of ICS services fell short of the expected standard and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death. 16.7% of completed reviews were graded below a 3 indicating that the responsiveness of ICS services either fell short of the expected standard and this impacted in the person's wellbeing but did not contribute to the cause of death, or that the responsiveness of ICS services fell far short of the expected standard and this contributed to the cause of death. 42.8% of reviews were graded as 4 and 5 combined indicating the responsiveness of ICS services either fell short of the expected standard in some areas, but this did not significantly impact on the person's wellbeing, or that the responsiveness was good and met the expected standard. No reviews were graded as 6 which indicates excellent responsiveness exceeding the expected standard.

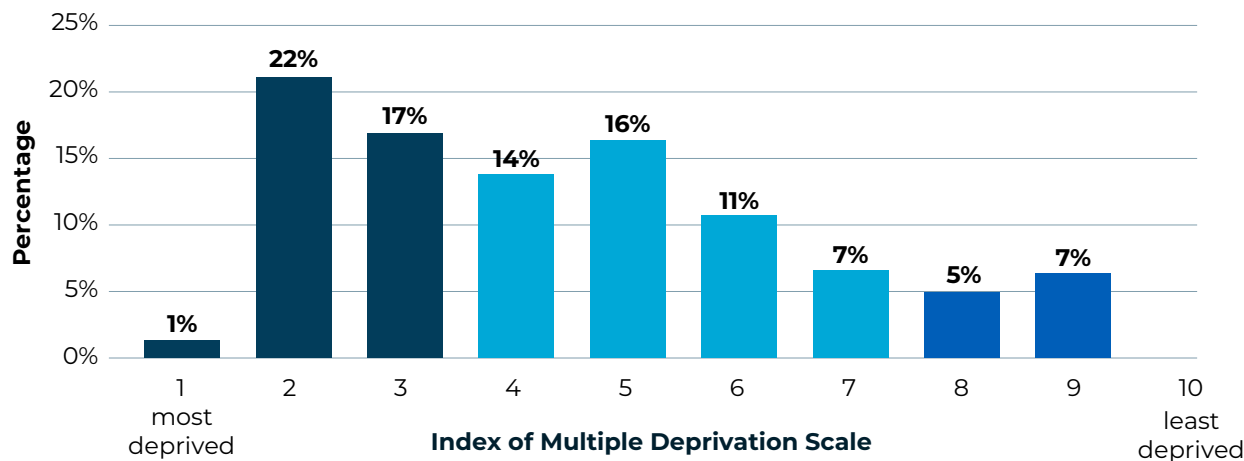
Table 3.0 **Grading of effectiveness of Integrated Care System Services**

1	Responsiveness of ICS services to the person's needs fell far short of the expected standard and this contributed to the cause of death
2	Responsiveness of ICS services to the person's needs fell short of the expected standard and this did impact on the person's wellbeing but did not contribute to the cause of death
3	Responsiveness of ICS services to the person's needs fell short of the expected standard and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death
4	Responsiveness of ICS services to the person's needs fell short of the expected standard in some areas but this did not significantly impact on the person's wellbeing
5	Responsiveness of ICS services to the person's needs was good and met the expected standard
6	Responsiveness of ICS services to the person's needs was excellent and exceeded the expected standard

Deprivation index

The Index of Multiple Deprivation (IMD) scale shows that 40.0% of adults whose deaths were reported to the NHS South East London LeDeR team in 2024-2025 lived in the most deprived areas (1-3) and 12.0% of adults who died lived in the least deprived areas (8-10).

Figure 2.2 **Deprivation index recorded for each LeDeR review completed between April 2024 and March 2025**



Long term conditions

Data from 2024-2025 shows a high burden of complex, long-term health conditions among people with a learning disability and autistic people, with many experiencing multiple and overlapping needs. The most prevalent conditions were gastro-intestinal problems (53.6%), mobility difficulties (50.0%), sensory difficulties (48.7%) and continence problems (47.5%), all of which significantly affect daily functioning, independence and quality of life. High-risk clinical conditions were also common, including dysphagia (41.4%), epilepsy (36.5%) and cardiovascular disease (31.7%), alongside a substantial prevalence of hypertension (30.5%) and mental health conditions (26.8%). Cancer and stroke were each identified in 14.6% of cases. Overall, the findings highlight significant levels of multi-morbidity and preventable risk, reinforcing the need for proactive, coordinated care and embedding reasonable adjustments into healthcare to reduce avoidable harm and premature mortality in this population.

Table 3.1 **Most common long-term health conditions recorded by the reviewer for reviews completed between April 2024 and March 2025**

Long Term Health Conditions	Percentage
Gastro-intestinal Problems (Including constipation)	53.6%
Mobility Difficulties (Including mobility aids and frequent falls)	50.0%
Sensory Difficulties	48.7%
Continence Problems (Including urinary tract infection and incontinence)	47.5%
Dysphagia	41.4%
Epilepsy	36.5%
Cardiovascular Disease (excluding hypertension/stroke)	31.7%
Hypertension	30.5%
Mental Health Condition	26.8%
Cancer	14.6%
Stroke	14.6%
Asthma/Chronic Obstructive Pulmonary Disease (COPD)	13.4%
Diabetes	10.9%
Chronic Kidney Disease (Renal)	9.8%
Body Mass Index (BMI) over 30	8.5%
Deep Vein Thrombosis (DVT)	3.6%
Dementia	2.4%

Transition

Children and young people receive health and social care services until the age of 18, after which support is usually provided by adult services. This transition period is a critical stage. In 2024-2025, we completed less than five reviews for people who died aged between 18 and 25. Of these, 33.0% were initial reviews and 66.0% were focused reviews.

Health conditions

All reviews showed the presence of complex health needs including gastrointestinal conditions, incontinence, and mobility issues. Two thirds (66.0%) of the people reviewed had a diagnosis of dysphagia.

Findings

Overall, the reviews indicated that young people transitioning from Children's to Adult services generally received good quality care. However, the reviews identified opportunities to strengthen transition processes, particularly through earlier planning and improved communication between professionals involved in their care.

Conclusion

The reviews provide assurance that the overall standard of care was positive. However, they also highlight the importance of robust transition arrangements, including proactive planning and effective inter-professional communication, to support continuity of care and positive outcomes for young people with a learning disability.



Themes identified in completed reviews – positive practice and issues

Positive practice

Of the 82 LeDeR reviews completed between April 2024 and March 2025, evidence of positive practice was identified in 67 (82.0%) of the reviews. Below is a summary of some of the positive practice identified:

- **Multi-disciplinary working:**
We saw excellent examples of multidisciplinary working where professionals from the Community Learning Disability Teams, Mental Health in Learning Disability Teams and GP surgeries worked collaboratively to provide holistic person centred care.
- **Reasonable adjustments:**
Some examples include health professionals meeting the person at an alternative location more suited to the person, extra time given for appointments, use of easy read materials to help explain procedures and the use of communication tools to explore pain.
- **Stopping over medication of people with a learning disability and autistic people (STOMP):**
Care provider staff having a good understanding of psychotropic medication and side effects to ensure individuals were not being inappropriately prescribed psychotropic medications.
- **Acute Learning Disability Liaison Nurse:**
On admission to hospital the liaison nurse ensured that hospital staff were made aware of any reasonable adjustments required and the use of hospital and communication passports.

Issues

From the LeDeR reviews completed between April 2024 and March 2025 we identified the following common themes/issues and present a summary of these below:

- **Do Not Attempt Cardiopulmonary Resuscitation (DNACPR):**
DNACPR documentation not being completed correctly, health professionals not being aware that a DNACPR was in place, and family not being consulted that a DNACPR was in place.
- **Inaccurate cause of death:**
Learning disability improperly or inaccurately listed as a primary cause of death, on death certificates. It is important to note that whilst learning disability is a lifelong condition, it is not in itself a terminal illness.
- **Legal powers:**
Some reviews show that information relating to Lasting Power of Attorney (LPA) for health and welfare and property and financial affairs were not always documented correctly in patient records, leading to confusion amongst professionals and family members.
- **Lack of documentation to show adherence to the Mental Capacity Act (MCA):**
When a person was deemed to lack capacity, health and social care records did not always record the Mental Capacity Assessment and the best interest making decision process.



Chapter three

Completed reviews – Global majority

Introduction to the chapter, what it includes:

This chapter summarises the global majority data collected from LeDeR reviews completed by NHS South East London between April 2024 and March 2025. In line with NHS South East London policy, we use the term global majority to refer to people who are 'Black, Asian, Brown, dual-heritage, indigenous to the global south, and or have been racialised as ethnic minorities' (Campbell-Stephens 2020). For the NHS South East London LeDeR programme, the term global majority therefore includes people from Roma, Gypsy or Traveller backgrounds. The national LeDeR programme uses the term 'people from ethnic minority groups' to refer to this group of people.

Inequalities in access to care, experience of care, and care outcomes persist for people with a learning disability and autistic people from global majority groups. Previous LeDeR data analyses have highlighted significant differences in age at death, with global majority groups dying at a younger age, in comparison to those whose ethnic group was recorded as white (National LeDeR report 2022-2023).

Due to the small number of reviews completed for different global majority backgrounds in 2024-2025, this reports presents available data from the global majority population as a whole in this chapter. However, we acknowledge that people from the global majority are not a homogenous group and are likely to experience health inequalities in different ways. We hope to do more detailed analysis in future reports as we complete more reviews.

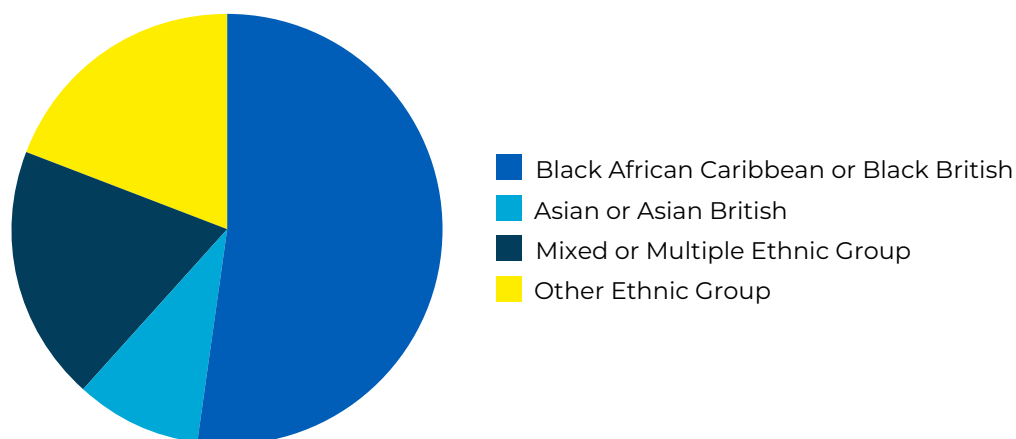
Number of reviews completed

Of the 82 reviews completed in 2024-2025, 21 (17.0%) reviews were recorded as being for people from a Global Majority background. As per the 2021 national LeDeR policy, all these reviews were completed as focused reviews.

Global majority background

Of the 21 reviews completed of people from a global majority background between April 2024 and March 2025, most were recorded as being Black African, Caribbean or Black British. Fewer than five reviews were recorded in each of the Asian or Asian British, Mixed or Multiple Ethnic Group, and Other Ethnic Group categories.

Figure 2.3 **The ethnicity breakdown of the 21 people reviewed from a Global Majority background**



Median age of death

The median age at death for people with a learning disability and autistic people from a global majority background in reviews completed between April 2024 and March 2025 is 56 years.

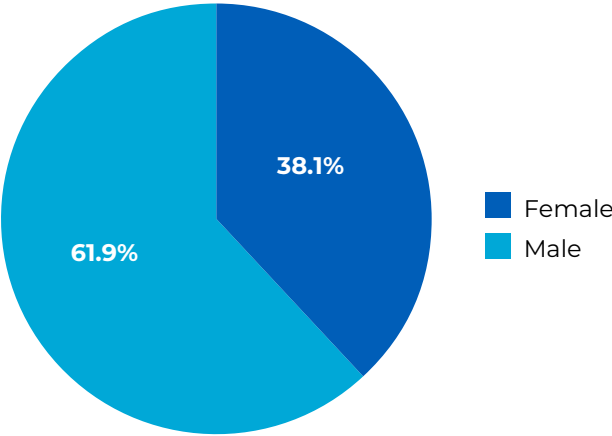
Due to the small number of deaths within some age groups, detailed tabulated data has not been presented to protect the confidentiality of individuals and to minimise the risk of identification.

The age distribution of deaths among people from global majority communities was skewed towards middle and older age groups. Most deaths occurred among individuals aged 46-65 years, with the 56-65 age group accounting for the largest proportion. Comparatively few deaths were reported among younger adults and those aged over 75 years, and no deaths were recorded in several age groups. This pattern suggests that mortality within this cohort was predominantly concentrated among people in later adulthood rather than younger or very old age groups.

Gender

Of the 21 reviews completed of people from a global majority background in 2024-2025, eight (38.1%) were female and 13 (61.9%) were male. This reflects a long-reported pattern of a higher proportion of male reviews being completed across all ethnicities.

Figure 2.4 **Reviews completed of people from a global majority by gender**



Type of patient

Of the 21 reviews completed of people from a global majority background in 2024-2025, most were for people with a learning disability. Fewer than five reviews were for people with both a learning disability and autism and for autistic people without a learning disability combined.

Level of learning disability

Of the 19 reviews completed of people from a global majority background who had a diagnosis of learning disability in 2024-2025, the most common levels of learning disability recorded were mild and severe. Fewer than five reviews related to people with moderate or profound learning disability combined.

Completed reviews by borough

Of the 21 reviews completed of people from a global majority background in 2024-2025, the highest number were from Lambeth, followed by Lewisham. Fewer than five reviews were completed for Greenwich and Southwark, and fewer than five were completed across Bexley and Bromley combined.

Table 3.2 **Number of reviews completed for people from a global majority per borough**

Borough	Number of deaths of people from a Global Majority Number (%)
Bexley	**
Bromley	0.0%
Greenwich	**
Lambeth	42.9%
Lewisham	23.8%
Southwark	**
Total	100%

Place of death

The people from a global majority who were reviewed between April 2024 and March 2025 died in two different locations, in hospital (14) or at their usual place of residence (seven).

Table 3.3 **Place of death for people from a global majority**

Place of death	Number of deaths of people from a Global Majority Number (%)
Hospital	14 (66.7%)
Usual residence	7 (33.3%)
Hospice	0 (0.0%)
Mental health Unit	0 (0.0%)
Other	0 (0.0%)
Total	21 (100%)



Cause of death

Pneumonia remained the most commonly recorded cause of death among people from a global majority background whose reviews were completed between April 2024 and March 2025. The pneumonia-related deaths included a range of presentations, including aspiration pneumonia, community-acquired pneumonia, hospital-acquired pneumonia, bronchopneumonia and parainfluenza pneumonia. A small number of deaths were attributed to heart failure, while the remaining reviews recorded a variety of other causes of death. Consistent with findings from 2023-2024, pneumonia continues to be the most frequently reported cause of death among both people from global majority communities and those whose ethnicity was recorded as White.

In line with statistical disclosure control principles, detailed counts for specific causes of death have not been reported where there is a risk that individuals could be identified from small numbers.

Cause of death by gender

Table 3.4 **Most common causes of death for people from a global majority between April 2024 and March 2025 by gender**

Rank	Male – % of Male Deaths	Female – % of Female Deaths
1st	Pneumonia: 46.2%	Pneumonia: 25.0%
2nd	Other: 53.8%	Heart Failure: 25.0%
3rd		Other: 50.0%

Cause of death by borough

Table 3.5 **Most common causes of death for people from a global majority between April 2024 and March 2025 by borough**

Borough	Cause of death (% , within borough)
Bexley	Other: 100%
Bromley	No deaths notified
Greenwich	Heart Failure: 25.0% • Other: 75.0%
Lambeth	Pneumonia: 55.6% • Heart Failure: 11.1% • Other: 33.3%
Lewisham	Pneumonia: 40.0% • Other: 60.0%
Southwark	Other: 100%

Cause of death by age group

Table 3.6 **Most common causes of death for people from a global majority in 2024-2025 by age group**

Age Group	Cause of Death (% , within age group)
18-25	No deaths notified
26-35	Other: 100%
36-45	No deaths notified
46-55	Pneumonia: 33.3% • Other: 66.7%
56-65	Pneumonia: 55.6% • Heart Failure: 11.1% • Other: 33.3%
66-75	Other: 100%
76-85	Heart Failure: 100%
Over 85	No deaths notified

End of life care plan

Of the 21 reviews completed for people from a global majority background in 2024-2025, eight reviews (38.1%) found that an end-of-life care plan had been in place at the time of the person’s death.

Deaths with DNACPR

Of the 21 reviews completed for people from a global majority background in 2024-2025, 10 reviews (47.6%) found that a DNACPR was in place at the time of the person’s death. Of these 10 reviews, eight (80.0%) found that the DNACPR had been discussed with the person or their family.

Referral to a coroner

Deaths are reported to a coroner in certain circumstances, for example: deaths where the cause is known, suspicious or unnatural deaths, deaths resulting from accidents, deaths that occur in custody or detention, where a doctor has not seen the person in the last 28 days or deaths linked to medical treatment or surgery.

Of the 21 reviews completed for people from a global majority background in 2024-2025, six reviews (28.6%) were reported to the coroner.

Learning disability register and the learning disability annual health check

Of the 19 reviews completed in 2024-2025 for people from a global majority background who had a diagnosis of learning disability, 19 (100%) of people were on the learning disability register.

Of the 19 LeDeR reviews completed for people from a global majority background who had a diagnosis of learning disability, 15 (79.0%) people were recorded as having an annual health check in the last 12 months before death.

Table 3.7 **Number of reviews completed for people from a global majority where the person was on the Learning Disability Register and had an annual health check in the last 12 months before death**

	Number of deaths of people from a Global Majority Number (%)
People on the Learning Disability Register	19 (100%)
People who had an annual health check in the last 12 months before death.	15 (79.0%)

Social care package

Reviewers are asked to state whether the social care package in place appeared to have met the needs of the person who died. Of the 21 reviews completed in 2024-2025 for people from a global majority, 95.2% were deemed by the reviewer to have had a care package that met their needs.

Deprivation index

In line with statistical disclosure control principles, detailed counts for some deprivation categories have not been reported due to the risk of identifying individuals from small numbers. Analysis of deprivation data indicates that people from a global majority background whose deaths were reviewed predominantly lived in the more deprived areas of south east London. Reviews were concentrated among people living in neighbourhoods with lower Index of Multiple Deprivation (IMD) scale scores, with scores between 1 and 4 representing the most deprived areas and scores closer to 10 representing the least deprived areas. The median Index of Multiple Deprivation (IMD) scale score was 3, demonstrating that most reviewed individuals lived in areas experiencing relatively high levels of socioeconomic deprivation. This finding is consistent with evidence linking deprivation to poorer health outcomes and health inequalities experienced by people with a learning disability.

Themes identified in completed global majority reviews – positive practice and issues

Issues

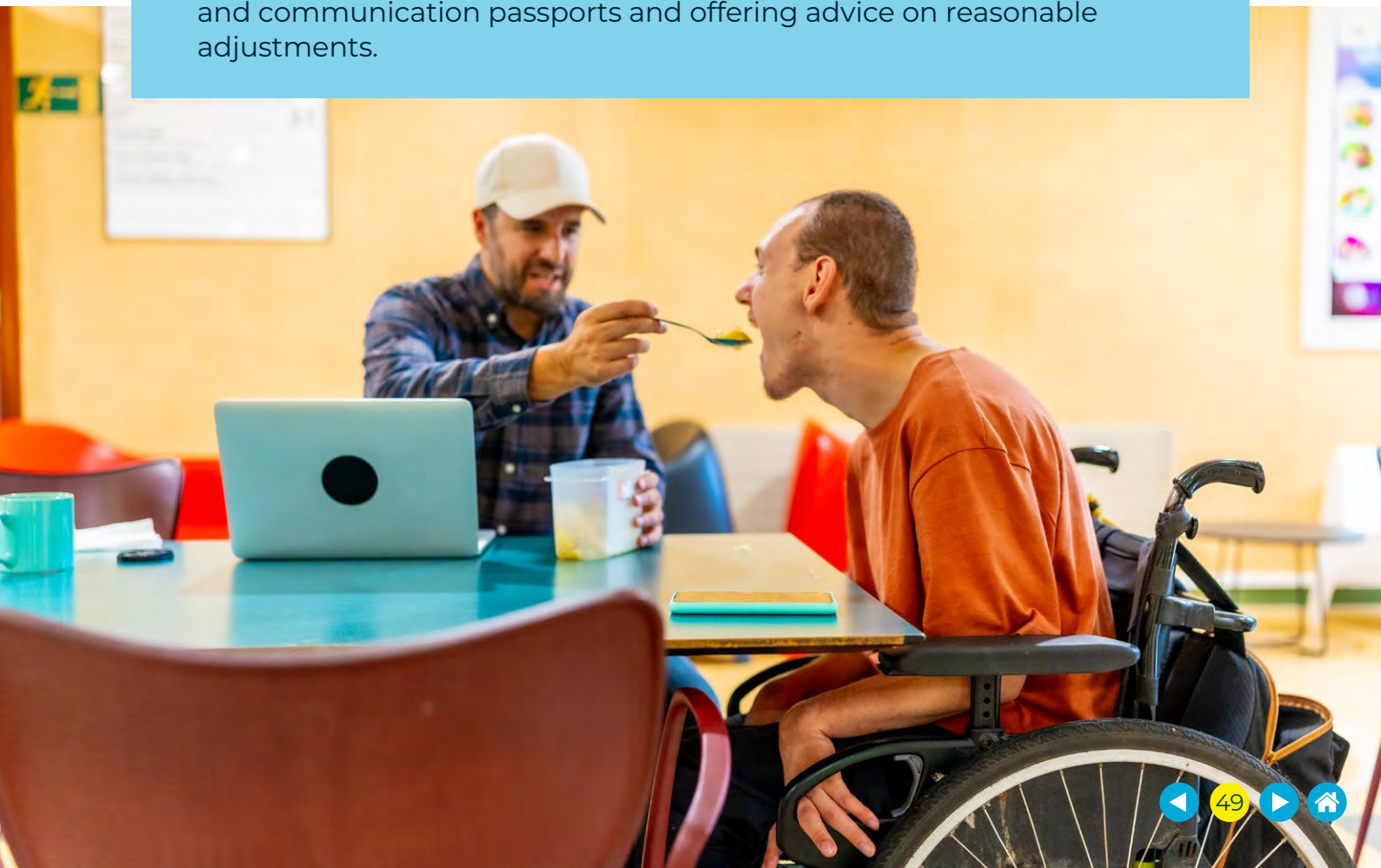
Of the 21 LeDeR reviews completed between April 2024 and March 2025 for people from a global majority, the reviewer identified at least one issue in all reviews. Below are key themes from the issues identified.

- No hospital passport available or hospital passport not being used by hospital staff.
- **Lack of response or delays in response to safeguarding concerns:**
These delays or lack of response were due to a variety of reasons, but they appeared to relate predominantly to concerns regarding self-neglect.
- **Family members not feeling listened to by professionals:**
This particularly related to hospital care.
- **Inconsistent records of diagnoses across services:**
A number of reviews found inconsistencies in several different diagnoses including level of learning disability. Inconsistencies occurred across multiple services including GP practices, social care and community learning disability teams.
- **Care packages not reviewed:**
A number of reviews showed that the care package in place had not been reviewed for up to four years.
- Referrals not made to acute learning disability nurses when people were admitted to hospital.
- **Poor adherence to the Mental Capacity Act including:**
Failure to assess capacity when indicated in relation to significant decisions, Inaccurate recording of the legal powers of family members without evidence being requested and family members making decisions on behalf of a person without best interest processes being followed, including declining treatment.

Positive practice

Of the 21 LeDeR reviews completed between April 2024 and March 2025 for people from a global majority, the reviewer was able to identify positive practice in 18 (85.7%) of the reviews. Below are key themes from the positive practice identified:

- **Continuity in professional support:**
Reviews showed the positive impact of a person having continuity in the professional support that they received. For example, seeing the same GP so that they were able to better understand the person's needs and adapt their approach to care accordingly.
- **Support from staff who knew the person well:**
Reviews highlighted the importance of support staff having in-depth knowledge of the person they were supporting. This particularly related to support to attend medical appointments. Staff who knew the person well were able to provide accurate and detailed information on the person's health needs, advocate on the person's behalf and ensure that appropriate reasonable adjustments were made where necessary.
- **The work of the acute hospital learning disability liaison nurses:**
The role of acute hospital learning disability liaison nurses was shown to have a positive impact on a person's care and wellbeing during hospital admissions. For example, by promoting the use of hospital and communication passports and offering advice on reasonable adjustments.



Chapter four

Area of focus

Cancer care in people with a learning disability and autism

London Ambulance Service involvement

Introduction to the chapter, what it includes:

An area of focus refers to a specific aspect of care, service delivery or care practice identified during review completion that requires closer attention for further learning. Between April 2024 and March 2025, reviews were converted to focused reviews under two areas of focus.

A. Reviews of a cancer related death

B. Reviews where the London Ambulance service were involved in the last episode of care



A Reviews of cancer related death in people with a learning disability and autism

People with a learning disability and autistic people face substantial disparities in cancer diagnosis and treatment compared with the general population. National and academic data highlight significant gaps, which include people with a learning disability experiencing delayed specialist assessment including screening leading to delayed diagnosis and poorer outcomes, including higher mortality.

During 2024-2025, in south east London one of our areas of focus was cancer care in people with a learning disability and autism. This section provides an overview of findings from the review of five deaths of individuals with a learning disability and complex health needs, including a cancer diagnosis. These reviews were completed as focused reviews.

Overview of cases

Focused reviews were completed for five cancer-related deaths in 2024-2025. Most reviews were converted to a focused review because the death was cancer-related, while a small number were also converted because care concerns had been identified. The five individuals reviewed were aged between 56 and 76. The median age was 66. All reviews were of White British people. Most were female. Most people had a learning disability without autism, while fewer than five had both a learning disability and autism. All were recorded as being on the GP learning disability register. Fewer than five had received an annual health check in the year before they died, while most had received a medication review. Most had a DNACPR decision in place. All had varying levels of learning disability (mild to moderate), and most had co-existing physical and mental health conditions.

The types of cancer were:

- Lung cancer
- Oesophageal cancer with liver metastasis
- Myeloid Leukaemia
- Lymphoblastic Leukaemia
- Breast carcinoma

Key findings

Difficulties in assessment and diagnosis

- Delayed diagnosis and rapid deterioration
- Delayed diagnosis and missed opportunities, especially where presentations do not align with atypical symptoms
- Delays in recognition and late referrals reduced opportunities for early intervention

Lack of reasonable adjustments

- Missed annual health checks, GPs declining to complete home visits, and limited reasonable adjustments affected access to timely care
- In some cases, diagnostic procedures (e.g. CT scans) were not completed due to lack of reasonable adjustments. Particularly not ensuring that information is explained to the person in a way that they could understand what was going to happen and what would be expected of them
- Learning disability flags were absent in some medical records, delaying specialist input

Lack of adherence to Mental Capacity Act

- Lack of capacity assessments regarding ability to consent to treatment plans
- In some of the reviews, Independent Mental Capacity Advocates (IMCA) were not involved despite some of the people lacking capacity and not having close family or friends involved to advocate for them

Inconsistent End-of-Life Care planning

- Several individuals lacked a documented end-of-life care plan
- Some end-of-life pathways were implemented late or not at all

Good Practice Identified

- Two individuals received comprehensive health care, including vaccinations, screenings, and reasonable adjustments (e.g. extended appointments)
- The involvement of an IMCA in two cases supported best-interest decisions and capacity assessments during hospital care
- Person centred practice to ensure that procedures and treatments are explained to the person in ways that suits them
- Support staff who knew the person well were involved in treatment and recovery
- Specialist community learning disability teams provided support

Recommendations for cancer care improvement in LeDeR reviews completed in south east London

1. Improve early detection and diagnosis

Strengthen cancer screening pathways and improve referral practices for individuals with a learning disability.

2. Standardise use of reasonable adjustments

Ensure consistent delivery of reasonable adjustments, including diagnostic accommodations and home visit options.

3. Strengthen coordination of care

Improve communication between primary care, hospitals, and specialist teams, including the use of learning disability flags and shared care plans.

4. Enhance End-of-Life Care planning

Promote early, documented end-of-life discussions with appropriate IMCA involvement and family communication.

Conclusion

These reviews highlight persistent challenges faced by people with a learning disability and autistic people to access early cancer diagnosis, treatment and coordinated care. While examples of good practice exist, systemic improvements are needed to reduce health inequalities and provide person centred cancer care. Embedding proactive care, reasonable adjustments, and clear end-of-life planning will help deliver safer, more person centred healthcare in south east London.

B Reviews where the London Ambulance service were involved in the last episode of care

Four reviews completed in 2024-2025 involved the London Ambulance Service (LAS) in the person's last episode of care. Due to the small number of cases within this category, no consistent themes, patterns, or areas of learning could be reliably identified. As a result, we were unable to draw conclusions that would meaningfully inform recommendations for improving care for people with a learning disability and autistic people.



Chapter five

Addressing themes from the 2023-2024
NHS South East London LeDeR Annual Report

Introduction to the chapter, what it includes:

This chapter highlights projects commissioned and established by key stakeholders in south east London to address issues identified in the 2023-2024 NHS South East London LeDeR report.

Epilepsy project

In the 2023-2024 LeDeR Annual Report for South East London ICB, it was reported that out of 54 reviews completed, the average age of death for those with a diagnosis of epilepsy was 49 years. The highest cause of death for epilepsy related LeDeR reviews was pneumonia at 43.0%.

Adult patients with a learning disability and epilepsy in Bexley have their epilepsy managed by mainstream Adult Neurology or in Primary Care. The Bexley Community Learning Disability Team historically had no clinical expertise in managing epilepsy in this patient group. In response to LeDeR reports, and to meet the unmet epilepsy needs in Bexley, an epilepsy pathway within the Bexley Community Learning Disability Team was developed. Funding was made available for a full time Band 7 nurse and after successful recruitment the nurse was in post by June 2023. Some additional money was also made available to support the development of this service and provide training to the local providers of specialist learning disability services. A specialist support worker was recruited initially on a fixed term 12-month contract, with permanent funding agreed from April 2025 onwards.

This service is a specialist Consultant-led Epilepsy Service in Bexley, with the following aims and service delivery:

- To meet the epilepsy-related needs of people with a learning disability in Bexley and reduce morbidity and mortality.
- To contribute to a seamless transition of people with a learning disability and epilepsy from Paediatric to learning disability (or neurology) services.
- To help ensure that carers are taught about the key aspects of epilepsy, and where appropriate, trained in administering Rescue Medication.
- To liaise with Hospital Teams when Patients with a learning disability and epilepsy are admitted.
- To work strategically with NHS South East London ICS Commissioners in Bexley and Oxleas Senior Management on delivering effective and efficient Epilepsy Services locally.

Cancer care training module:

The South East London Cancer Care Alliance launched a new training module designed to help healthcare professionals better support people with a learning disability in accessing cancer care and screening services. The South East London Cancer Alliance collaborated with the **Baked Bean Charity** and the **Guys Cancer Academy**, to create the **Learning disabilities and cancer educational module**. The brilliant students from Baked Bean made sure the module remains authentic and includes information that matters most to people with a learning disability.

The module supports the improvement of cancer risk mitigation, patient experience, early diagnosis and ultimately better outcomes for this patient population. The module was designed for all primary care staff, but it does contain information for secondary care colleagues that may need to support someone with a learning disability, by providing the following:

- Highlighting the additional healthcare needs of people with a learning disability.
- Effective communication strategies tailored to the patient group.
- Reasonable adjustments you can implement, to improve accessibility for patients with a learning disability.
- Best practice in making cancer screening and health checks accessible for patients with a learning disability.
- How to create and maintain a supportive and inclusive practice environment.

The module is free and is not location specific, so it can also be used by professionals working outside of South East London.

learning.guyscanceracademy.co.uk/selca-cancercareforpeoplewithlearningdisabilities/index.html



RESTORE2 training:

People with a learning disability and autistic people experience significantly poorer health outcomes and often face difficulties accessing the health services that could help improve and maintain their physical health and wellbeing. They are more likely than the general population to experience poor health and are more vulnerable to deterioration in both physical and mental health.

RESTORE2 is a nationally recognised tool used by care providers to identify early signs of illness and deterioration. Healthcare professionals from the Oxleas Adult Learning Disability (ALD) Service have previously delivered training on RESTORE2 and the use of the SBARD communication tool to many service providers across the Bexley, Bromley, and Greenwich boroughs in south east London. The training focuses on identifying early “soft signs” of illness or deterioration. These are changes that can often be detected visually or through supporting individuals with their Activities of Daily Living (ADLs). The training also equips carers to communicate concerns more effectively to GPs, 111, or 999 services using a structured template.

SBARD is a structured communication framework and mnemonic. The template includes:

- **Situation:** What are the concerns about the individual? How long has this been happening?
- **Background:** How does the individual usually present, and how is this different from usual?
- **Assessment:** What has been observed or completed so far. For example, if staff have taken a temperature or administered pain relief
- **Recommendation:** What action or outcome is being requested
- **Decision:** What has been agreed following the discussion

Training was initially prioritised for services supporting individuals with multiple or complex physical health needs, as these individuals are more at risk of early deterioration and avoidable hospital admission. Once this cohort had been trained, the team expanded the offer to all providers across the three boroughs, including Shared Lives carers and carers’ groups upon request.

In response to findings from the 2023-2024 NHS South East London LeDeR Report, a refresher training package was developed. This updated version includes additional awareness on sepsis and constipation, which are known contributors to preventable deterioration and hospitalisation for people with a learning disability.

The updated training has been well received, and the Oxleas ALD team continues to work collaboratively to deliver it as widely as possible across Bexley, Bromley, and Greenwich. Over the last 12 months, multiple refresher sessions have been delivered, with consistently positive feedback. Carers report feeling more confident in recognising early signs of illness and in communicating their concerns clearly using the SBARD template. Importantly, this training has contributed to reducing avoidable hospital admissions, ensuring individuals receive timely and appropriate care and preventing further deterioration that could otherwise result in prolonged or unnecessary hospital stays.



Improving the access to the urgent suspected referral pathway for people with a learning disability and autism in south east London

King's College Hospital Cancer Quality Improvement Lead, with support from the Acute Learning Disability Nurses across the South East London Cancer Alliance (SELCA) have led on a project across King's College Hospital, Guy's and St Thomas', and Lewisham & Greenwich NHS Trust to improve processes to support people with a learning disability and autistic people referred onto urgent suspected referral (USR) pathways. The project aims to ensure timely diagnosis, consistent provision of reasonable adjustments, and improved communication across the pathway.

Phase 1: Improving booking and communication processes

Phase 1 focuses on improving the notification / communications of reasonable adjustments needed to support patients through their pathway. Primarily between booking/admin teams and Trust Learning Disability and Safeguarding teams.

Key achievements

- Development of a Standard Operating Procedure (SOP) and training package outlining required actions when referrals identify learning disability and or autism.
- Clear processes for contacting Learning Disability and Safeguarding teams, expected response times, and sharing reasonable adjustment information with clinical teams.
- Training delivered to booking and admin teams at King's College Hospital and Guy's and St Thomas Hospital. Training has been arranged for staff at Lewisham University Hospital.

Evaluation planned

- A follow-up staff confidence survey within three months to compare with baseline results.
- Case study reviews to assess whether clinical teams receive adjustment information in time to prepare for appointments.

Future Phases

Next steps will focus on:

- Improving information sharing from primary to secondary care, including completion of reasonable adjustment fields on e-referrals.
- Strengthening the use of best interest meetings to support decision-making.
- Supporting patients who are frequently known to not attend their appointments.
- Exploring digital flagging solutions for automatic identification of patients requiring reasonable adjustments.

Summary:

This work demonstrates services commitment to reducing overall delays and improving equitable access for people with a learning disability and autistic people. Early progress has improved consistency and staff understanding, with further phases planned to enhance communication, digital support, and pathway reliability.

NHS South East London All-Age Autism Strategy

To address the significant care gaps and to better meet the diverse needs of autistic people across south east London, an All-Age Autism Strategy has been developed by the NHS South East London Integrated Care Board (ICB). This strategy sets out a shared vision for improving support, reducing inequalities, and enabling autistic people of all ages to lead happier, healthier, and more fulfilling lives.

The NHS South East London All-Age Autism Strategy outlines how autistic people and their families will be supported across the six boroughs of south east London. Developed in partnership with autistic individuals, carers, and professionals, the strategy aims to strengthen early recognition, improve access to services, and reduce the health, social, and educational inequalities experienced by autistic people. It is accompanied by a regularly reviewed implementation plan.

The NHS South East London All-Age Autism Strategy estimated that around 21,000 residents (1.0% of the population) were autistic. Updated data now indicates that approximately 31,000 people have a recorded autism diagnosis across south east London, representing around 1.5% of the population. Autism presents differently in each person and may be accompanied by additional needs; around 40.0% of autistic people also have a learning disability, and up to 70.0% have co-occurring mental health or neurodevelopmental conditions. The strategy recognises the substantial inequalities autistic people face, including poorer health outcomes, reduced life expectancy, barriers in education and employment, and increased vulnerability within the criminal justice system. The strategy aligns with LeDeR recommendations to improve outcomes for autistic people.

The strategy focuses on eight key priority areas:

1. Improving recognition and understanding

Enhancing training and awareness across health, education, and community services to support early identification of needs and provide appropriate adjustments, including for individuals awaiting or not seeking a diagnosis.

2. Supporting families and networks

Ensuring families and carers have access to information, respite, peer support, and opportunities to connect within their local communities.

3. Tackling health and care inequalities

Reducing barriers to healthcare, improving diagnostic pathways, promoting reasonable adjustments, empowering autistic people to communicate their needs, and implementing Oliver McGowan training.

4. Improving access to inclusive local services

Ensuring autism-specific and lifespan-appropriate services are available in each borough, including post-diagnostic support and help during key transitions.

5. Building the right support in the community and improving inpatient care

Reducing avoidable inpatient admissions by strengthening community mental health and crisis pathways and ensuring high-quality, person centred inpatient care when required.

6. Ensuring fair access to education and better transitions to adulthood

Working with education and SEND services to increase inclusion, reduce exclusions and bullying, and improve outcomes for autistic children and young people through better supported transitions.

7. Supporting more autistic people into employment

Addressing the employment gap by improving employer confidence, promoting Access to Work, and strengthening employment support and workplace adjustments.

8. Keeping autistic people safe, including within the criminal and youth justice systems

Improving recognition, protection, and support for autistic people who may be at risk, victims of crime, or involved in the justice system, and working with police and justice partners to improve understanding of autism.

Implementation will be led locally by Autism Partnership Boards in each borough, involving autistic people, carers, health services, education, safeguarding, commissioning, and the Metropolitan Police. Progress will be monitored regularly, with annual reporting and updates to ensure continuous improvement.

Chapter six

Our commitment

Looking forward

Between 1 April 2024 and 31 March 2025, 82 LeDeR reviews were completed. The NHS South East London LeDeR team remains committed to acting on key areas of learning identified through both previous and current LeDeR reports.

Over the coming year, the NHS South East London LeDeR team will:

- Continue to focus on improving the timeliness and quality of LeDeR reviews to ensure learning is identified and shared as promptly as possible.
- Continue to raise awareness of the LeDeR programme across south east London, with a particular focus on increasing awareness of autism only LeDeR reviews among non-learning disability specialist services.
- Continue to promote the embedding of learning from completed LeDeR reviews into service improvement through established LeDeR governance processes across the six boroughs in south east London. Learning and actions arising from LeDeR reviews will continue to be monitored through established borough-level and NHS South East London ICB governance structures to provide assurance and oversight.
- Continue to develop engagement activities that promote LeDeR discussions and support the strengthening of health and social care pathways for people with a learning disability and autistic people.
- Continue to work collaboratively with providers to reduce preventable deaths of people with a learning disability and autistic people across south east London.
- Continue to support system-wide efforts to reduce health inequalities by identifying patterns and themes of unmet need and variation in access to care for people with a learning disability and autistic people.

