South East London Integrated Care System

NHS South East London

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

Annual Report 2023-2024

Contents

Acknowledgments

The South East London (SEL) LeDeR team would like to thank the following people without whom the reviews and learning would not have been possible

- Families and carers of those who have lost someone dear to them. Your voice has been invaluable in helping us learn about your loved one's experience, and your experience, of using local health and social care services. This has helped us to better understand what works well and identify areas that we need to improve.
- South East London (SEL) ICB LeDeR team and Positive Support Group (PSG), who have endeavoured to truly understand the people at the heart of the LeDeR reviews. Not only do the reviews show an understanding of each person as an individual, but they also reflect what was important to each person throughout their life. Without their expertise, experience, and passion we would not be where we are.
- All local service providers and local authorities who have given us information to help us complete the reviews and for giving the LeDeR programme the attention it requires. Without this information we would not understand the care provided to each person.
- All members of the LeDeR Focused Review Panel and LeDeR Strategic Group.
- All SEL LeDeR Local Leads.
- NHS England Regional team.
- NHS England National team.

Executive Summary

This is the 5th annual report of the learning from lives and deaths for people with a learning disability and autistic people (LeDeR) for South East London Integrated Care System (ICS).

This report presents the data gathered from the 54 reviews completed, as well as highlighting local initiatives and projects across South East London. It is important that we continually drive improvement and focus on the learning from LeDeR and embed it into our everyday practices to reduce inequalities and ensure people with a learning disability and autistic people have the best opportunity to live a healthy life.

In 2023-2024 we received 82 LeDeR notifications and completed 54 reviews. Of the 54 reviews completed, 56% were initial and 44% focused. 59% were male, 39% female and 2% preferred not to state a gender. The recorded age at death ranged between 19 and 99, the median age of the persons reviewed was 59 years.

In January 2022, the LeDeR programme started reviewing deaths of adults known to have a formal diagnosis of autism. Like many other areas, South East London has so far received very small numbers of notifications for autistic adults with only four in 2023-2024. We know that this is not representative of the South East London population and therefore further work is needed to increase awareness of the inclusion of autistic adults within LeDeR and encourage notifications to be made for this cohort. As a result, this report predominately focuses on findings from people with a learning disability.

The reviews completed have shown pneumonia, cancer, and sepsis to be the top causes of death in people with a learning disability and autistic people. Although, nationally, we have seen a significant reduction in the number of Covid-19 deaths, this remains a risk. We will remain mindful of this as we continue to review the lives and deaths of people with a learning disability and autistic people this year and beyond.

Reviewers have identified many areas of good practice however we continue to record similar gaps as in previous years. Uptake of national cancer screening programmes remains low compared to the general population and there is more work to be done to ensure reasonable adjustments are put in place as well as improve the quality of annual health checks.

Introduction

The six boroughs of South East London (SEL) - Bexley, Bromley, Greenwich, Lambeth, Lewisham, and Southwark have a population of over two million people. In 2023-2024 South East London ICS was responsible for the health and care of the 10,077 people registered at a GP practice in South East London recorded as having a learning disability and 24,903 people confirmed by their GP as having a formal diagnosis of autism.

Figure 1.0 SEL learning disability population

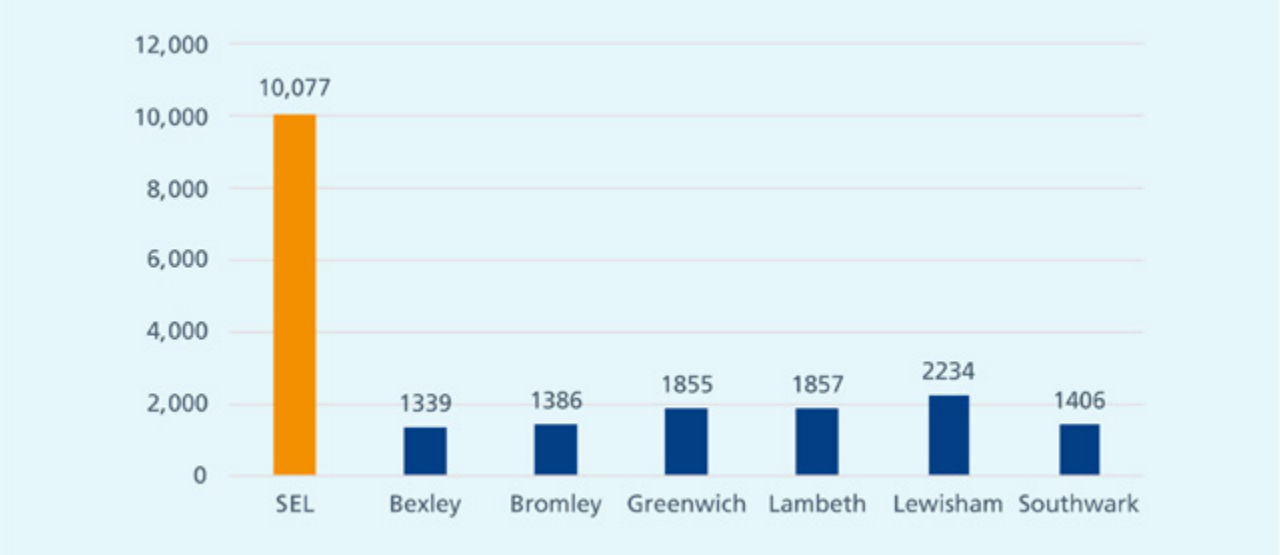
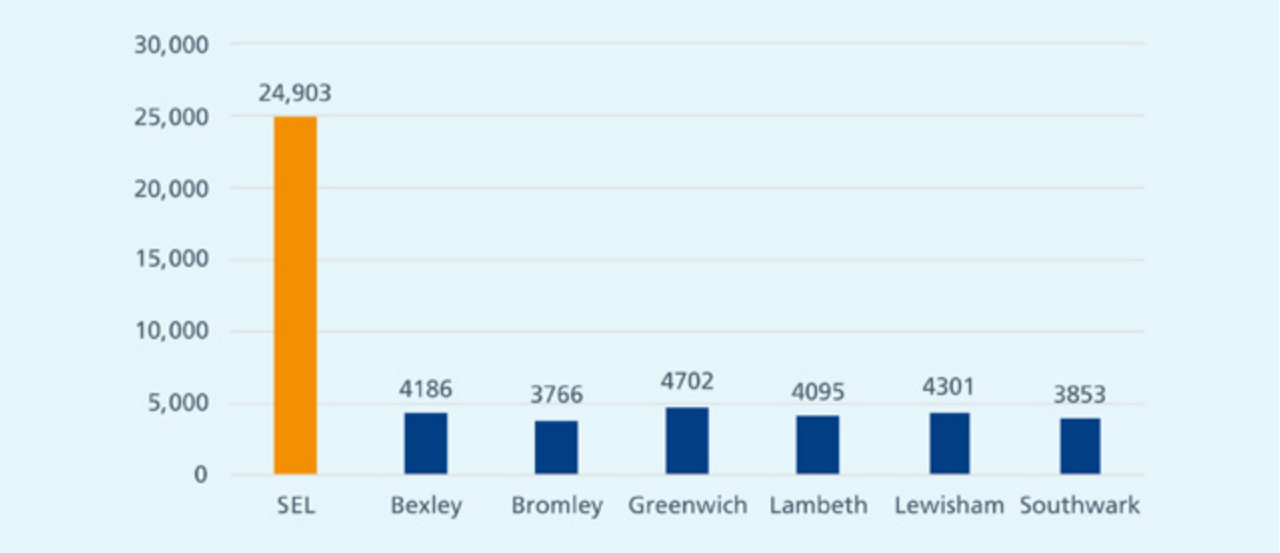


Figure 1.1 SEL autism population



Foreword

As Chief Medical Officer and Chief Nursing Officer we know just how important it is for the NHS to get it right for people with a learning disability, autistic people, and their families.

The LeDeR programme is one of a number of programmes and workstreams that sit within the South East London Learning Disability and Autism Programme.

Our vision is for people with a learning disability and autistic people to achieve equality of life chances, live as independently as possible and to have the right support from mainstream health and care services.

Our 5th annual report, highlights that despite improvements in previous years those with a learning disability and autistic people are still dying younger than the general population from conditions that can be mainly avoided through effective prevention or treatment. Therefore, it is imperative that we continually drive improvement and focus on the learning from LeDeR and embed it into our everyday practice to reduce inequalities and ensure people with a learning disability and autistic people have the best opportunity to live a healthy life.

The Oliver McGowan mandatory training in learning disability and autism is currently rolling out across England as all regulated service providers must now ensure their staff receive learning disability and autism training appropriate to their role. Learning taken from completed LeDeR reviews is featured in this training.

South East London ICB were an early implementer of a Learning From Deaths Group. The aim of this senior group of attendees from across the ICS, is to provide a forum to bring together all mortality related incidents and events, to identify areas of good practice and disseminate the learning. The SEL Learning From Deaths Group aims to improve and drive further improvements. The group will bring together themes, patterns from learning from deaths, across all areas and patient cohorts. The LeDeR programme is a core part of that group, enabling the themes for improvement to be flagged across all services in South East London.

This annual report also includes examples of successful local initiatives across South East London that are already making healthcare access, and interventions better for people with a learning disability and autistic people. There is still more to do.

Toby Garrood
Chief Medical Officer

Paul Larrisey
Acting Chief Nursing Officer

The LeDeR Process

All deaths of people with a learning disability and autistic people aged 18 years and over are eligible for a LeDeR review. Anyone, for instance, a family member, a friend, doctor, health professional, or a social worker can report the death of an autistic person or someone with a learning disability by submitting a notification to LeDeR via the LeDeR website.

The notification form includes basic demographic information about the person who died, such as their name, NHS number, address, date of birth, sex, and ethnicity. The person submitting the form is asked to provide information about the circumstances of death, including where the death occurred, cause of death if known, and whether they had any concerns around the care of the person. This information is then checked against the NHS Personal Demographic Service (PDS) database to check that the individual was a real person by checking their NHS number and personal information.

Notifications are also checked against the national data opt-out repository. Since 2021 LeDeR has enforced the National Data Opt Out (NDOO) so that any notifications for people who opted out of sharing their information for purposes other than direct care before their death are disregarded and reviews not completed. The NDOO was still in place during this annual report period (2023-2024). There were concerns that some people with a learning disability and autistic people may have been opted out by others inappropriately. NHS England successfully applied to the Confidentiality Advisory Group (CAG) for exemption from NDOO. Therefore, from April 2024, everyone with a learning disability and autistic people are now eligible for a LeDeR review regardless of whether they have opted out of NDOO, which will be reflected in future reports.

During this process, it may also become apparent that the notification is not suitable for LeDeR, for example, on further examination the deceased person did not have a clinical diagnosis of learning disability or autism in their records. In these cases, a LeDeR review is not completed, and the notification is marked as out of scope. In 2023-2024, ten notifications were marked as out of scope.

Once confirmed that the death is within scope of a LeDeR review, the LeDeR team requests health and social care records relating to the care received by the patient before death. The review is then allocated to a Reviewer with a target for this to be completed within six months from the date of notification. For some reviews, this will lead to a more comprehensive focused review, looking closer at the person's life and circumstances of death.

The LeDeR programme does not replace other statutory investigations and processes for reviewing a person's death but instead works alongside these processes. Where there are safeguarding adult reviews, serious incidents, complaints, or coroners' inquests, the LeDeR review is placed on hold until these processes conclude.

SEL Governance

The SEL LeDeR programme sits within the Learning Disability and Autism Programme which in turn is part of the Quality and Nursing Directorate and led by the SEL ICB Chief Nursing Officer. The team consists of a Local Area Contact (LAC) and Programme Lead, Programme Support Officer, Senior Reviewer, and two Reviewers.

Figure 1.2 SEL LeDeR team

We have successfully established a clear governance process to support the effective implementation of the LeDeR programme across South East London.

Figure 1.3 SEL LeDeR Governance

SEL ICS LeDeR Focused Review Panel

Focused reviews once completed are presented by Reviewers at the monthly SEL Integrated Care System wide focused review panel. The purpose of the panel to oversee completion of reviews and support the learning and actions from these reviews across SEL. With a clear set of Terms of Reference agreed by all panel members the SEL LeDeR team work closely with key partners across SEL. In 2023-2024 we held ten focused panels with a total of 24 focused reviews being presented to the panel.

LeDeR Strategic Group

With senior colleagues and experts by experience from across health and social care, all of whom have authority to implement change, the quarterly LeDeR Strategic Group provides assurance to the South East London Learning Disability and Autism Executive Group and Governing Body that SEL ICS is complying with the national LeDeR requirements and to also:

- Have oversight of ongoing LeDeR themes from completed reviews.
- To share learning from themes arising across all SEL LeDeR reviews.
- Receive feedback from each of the six London boroughs for ongoing or planned actions on how learning and recommendations will be applied to improve care provision for people with a learning disability and autistic people.
- Identify and share positive practice across the ICS.
- Child Death Overview Panel (CDOP) reviews - feedback from the six boroughs on ongoing or planned actions on how learning from CDOP reviews is completed and shared.

Local borough LeDeR steering group

In addition, each South East London borough is working towards developing a local LeDeR Steering Group. The purpose to:

- Support the work of the SEL LeDeR programme by looking at completed reviews and learning from the deaths of people with a learning disability and autistic people.
- Share wider SEL LeDeR learning at a local level.
- Increase awareness of the experiences of people with a learning disability and autistic people. This includes good practice, and areas where change is needed.
- Use learning to lead change in health and social care and education sectors.

Learning from Deaths Group (LFDG)

The LFDG provides a forum to bring together all SEL mortality related incidents and events including LeDeR to identify areas of good practice as well as disseminate the learning. The LFDG brings together themes, patterns and learning from the deaths with the aim of improving and driving further improvements in patient outcomes. Learning from LeDeR is shared in this forum, and themes from other stakeholders are fed back to the LeDeR Strategic Group.

LeDeR Audit

Our three-year South East London LeDeR Strategy (2023-2026) prioritises high-quality reviews. Before May 2022, an external agency handled these reviews. An NHS England audit of 2021-2022 reviews highlighted the need for quality improvements. In 2023-2024, with help from a Consultant Psychiatrist in Intellectual Disabilities, the South East London LeDeR team audited 2022-2023 reviews and found quality had improved.

Aim

Complete a quality audit of six LeDeR reviews completed by the South East London LeDeR Programme against the LeDeR Quality Assurance Audit Tool provided by NHS England.

Selection Criteria

- 6 reviews were selected at random.
- LeDeR reviews were completed in the 2022-2023 reporting year.
- 3 initial reviews and 3 focused reviews.
- Representation from each SEL London borough.

Method

Each section of the review was graded against the grading criteria using the NHSE audit tool.

Evidence was required to ascertain if each grading criteria was met. This included information such as completion of demographic details, details of death, mental capacity act, reasonable adjustments, end of life care, physical health assessments and screening. Additional information such as recommendations, key improvements and positive practice were also looked at. An overall grading of the review was then given based on the grading criteria below.

Grading Criteria

Figure 1.4 Grading criteria

GOOD	The review gives a clear picture of the health and care needs of the person and how they were or were not met The reviewer has evidenced efforts to engage family members and other people involved in the persons care and demonstrates an understanding of any gaps or issues which led to their death. The content of the review is predominantly of a high quality with no significant gaps in the information provided.
ACCEPTABLE	The reviewer has provided some information regarding the health and care needs of the person and how there were or were not met, however, the flow of information makes it difficult to form a clear picture of the person and the challenges they faced. The review provides enough information to capture learning / recommendations/ grading but with gaps in the information and / or quality issues.
REQUIRES IMPROVEMENT	The reviewer did not capture all the required information adequately. The flow of the review makes it difficult to interpret the needs of the person and the challenges they faced. There are gaps in key information that allow you to fully understand what led to their death or how this may have been avoided. There is a lack of professional curiosity to fully understand the sequence of events that led to the person's death or consideration of the SMART actions and recommendations to improve care.
UNACCEPTABLE	The reviewer had failed to capture the key information relevant to the review. There is no clear understanding of the persons needs or challenges or how there were met. The review has significant errors, for example, incorrect use of the person's name or gender; factual errors or gaps which would not meet professional record keeping standards.

Examples of Positive Practice

- Evidence of in-depth conversations with individual's families gave a clear sense of who the individual was, with recognition of any concerns raised.
- Concise, detailed summaries of past medical history that avoided jargon/direct copying from patient's notes.
- Reviewers identified shortfalls in the person's care e.g., lack of recent GP review.
- Safeguarding concerns were identified and recommendations for SAR review made.
- Reviewers had used information directly from the individual which allowed their voice to be heard.

Areas for improvement

- If the Reviewer is unable to contact family members, they should contact others involved in the person's care.
- Avoid repetition.
- Provide more information to carers/family about how they can access advocacy or support services.
- Avoid copying information directly from clinical notes and/or GP records with no evidence that reviewer spoke directly to care staff involved in person's care.

Conclusion

- All reviews were of a good or acceptable standard.
- Summary of discussion with family is an area which requires improvement.
- Reviews identified positive practice in clinical care, but also identified safeguarding concerns and deficits in individual's care.
- Areas of improvement include increased effort required to contact families/carers or when not able to, ensuring this was well documented and attempts made, avoiding repetition in reviews, and ensuring no missing information.
- Difficulties in contacting clinicians/carers may account for some of the missing information as well as access to death certificates/registration.

South East London LeDeR Demographics

Total number of LeDeR notifications received 2023-2024

A total of 82 LeDeR notifications were received in 2023-2024, the same number as in the previous year. Figure 1.5 shows the number of notifications received each reporting year since 2019, a total of 329 deaths.

Figure 1.5 Reported notifications by year since 2019

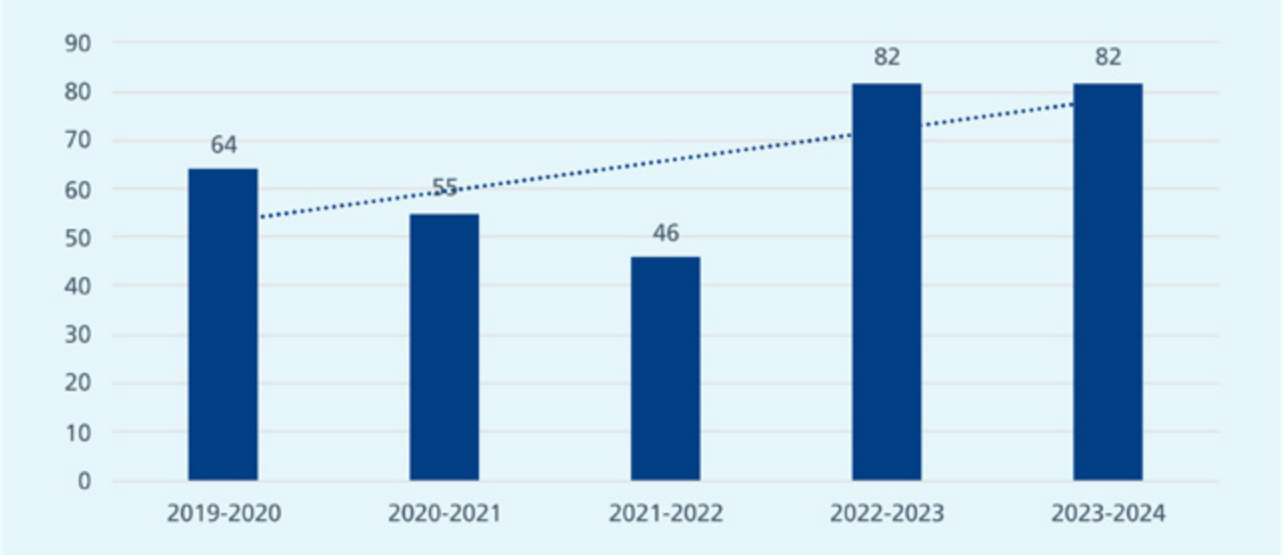
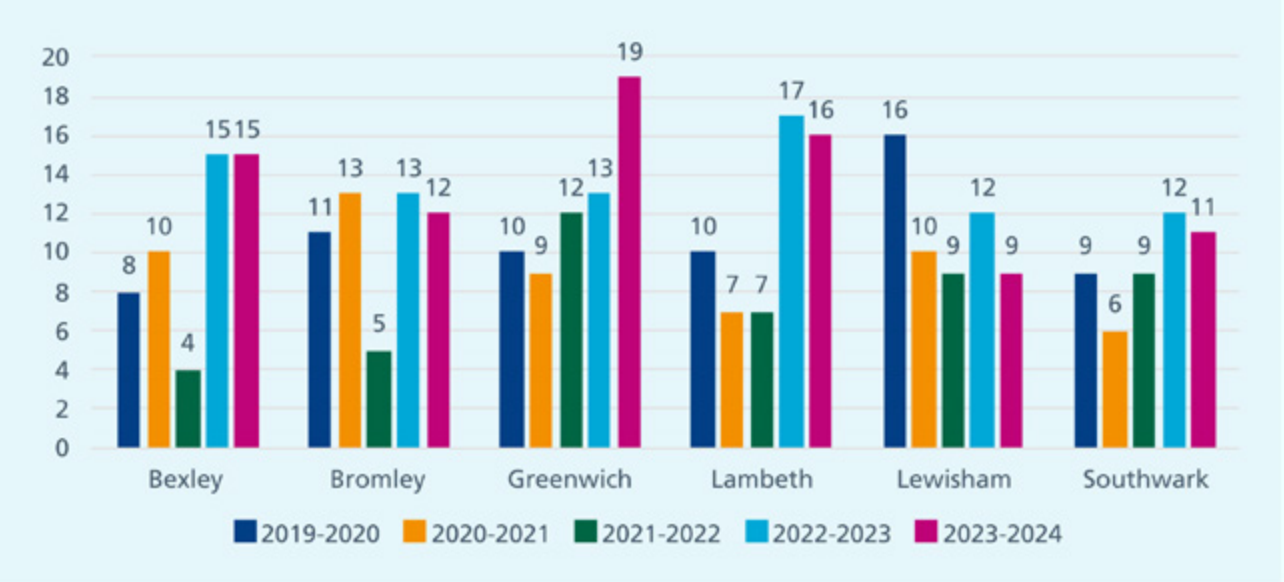


Figure 1.6 Number of LeDeR notifications received by borough since 2019



Type of review

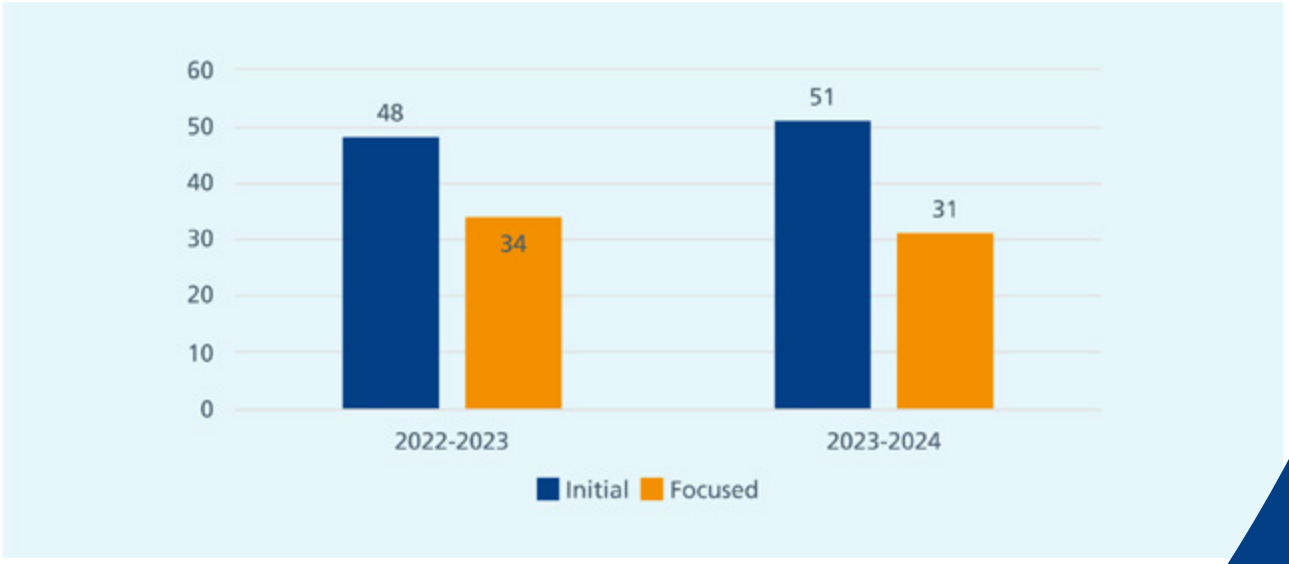
There are two types of reviews: initial and focused.

Initial reviews include a guided conversation with the family member or someone close to the person who died, a detailed conversation with the GP or a review of the GP records and a conversation with at least one other person involved in the care of the individual who died.

Focused reviews explore in more detail the life and death of the person and lessons that can be learnt from their care. The Reviewer with the help from the Senior Reviewer will use their professional judgement to decide whether a focused review is required.

In 2023-2024 the SEL LeDeR team received 51 initial reviews and 31 focused reviews. Of the 31 focused reviews six were converted from an initial review due to a local area focus on cancer deaths and/or care concerns.

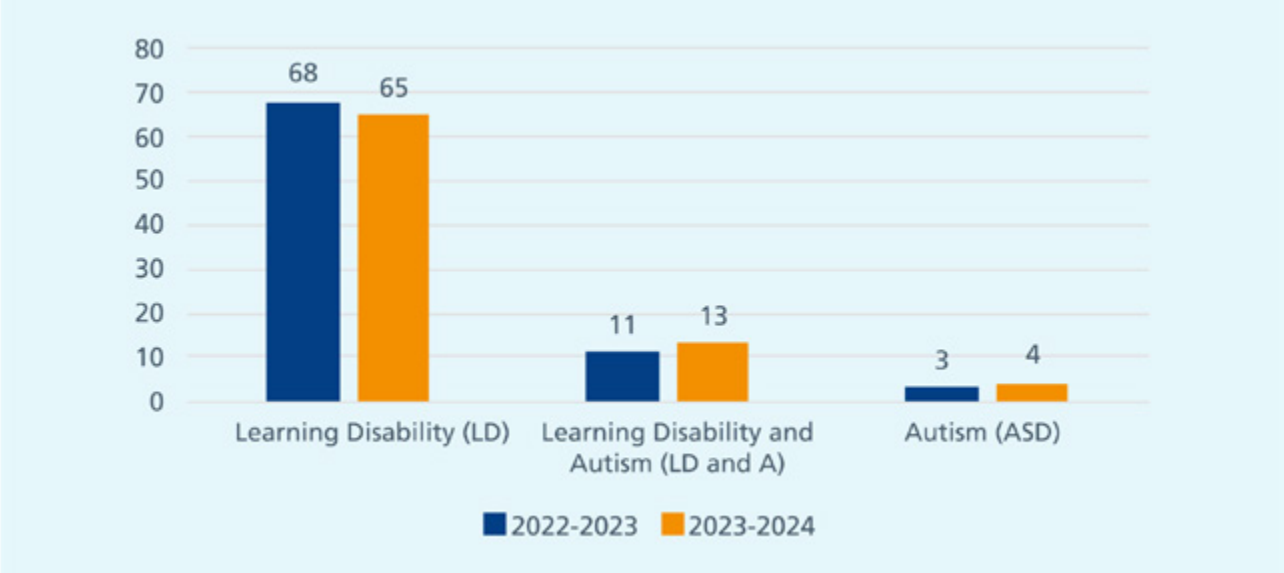
Figure 1.7 Number of LeDeR initial and focused reviews received in 22-23 and 23-24



Type of patient

Every adult (aged 18 and over) with a learning disability and/or with a clinical diagnosis of autism is eligible for a LeDeR review when they die. At the time of notification, the notifier selects the type of patient: (1) person with a learning disability (LD), (2) learning disability and autism (LD/A) and (3) autistic person who do not have a learning disability. In 2023-2024 we received four autism notifications, just one more than the previous year. Like many other localities the number of autistic notifications received is still very small. As a team we are continuing to work with local partners, to raise awareness that the deaths of autistic adults can be notified to LeDeR.

Figure 1.8 Type of patient



Age at death

From the 82 notifications received the recorded age ranged from 19 to 99 years. 50% of the deaths recorded were of people aged 66 years and above.

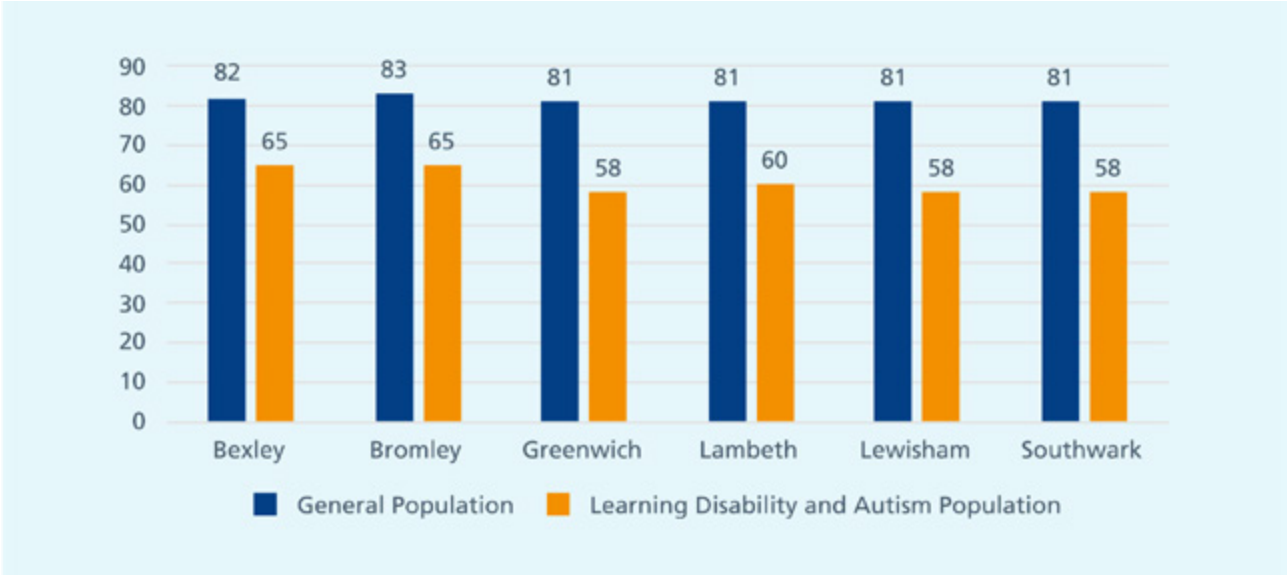
Table 1.0 Age groups

Age Group	Numbers	Percentage
18 - 25	4	5%
26 - 35	7	9%
36 – 45	2	2%
46 – 55	8	10%
56 – 65	20	24%
66 – 75	28	34%
76 - 85	12	15%
Over 86	1	1%

On average, women with a learning disability die 23 years younger and men 20 years younger when compared to the general population. The COVID 19 pandemic lead to increased mortality and the impact of this can be seen in the rate of increase in life expectancy slowing between 2020 and 2022. During this period, the Office of National Statistics reported that life expectancy at birth in the UK was 78.6 years for males and 82.6 years for females.

From the 82 LeDeR notifications received the median age of death for people with a learning disability and autistic people in South East London was 61 for males and 60 for females. Figure 1.9 shows how the median age differs from the general population but also how it differs from borough to borough. We acknowledge that the median age of a population can be impacted by the determinants of health including social, economic, environmental and behavioural factors. As a result, we will carry out a deeper analysis of the difference in median age between our boroughs in the 2024-2025 reporting year.

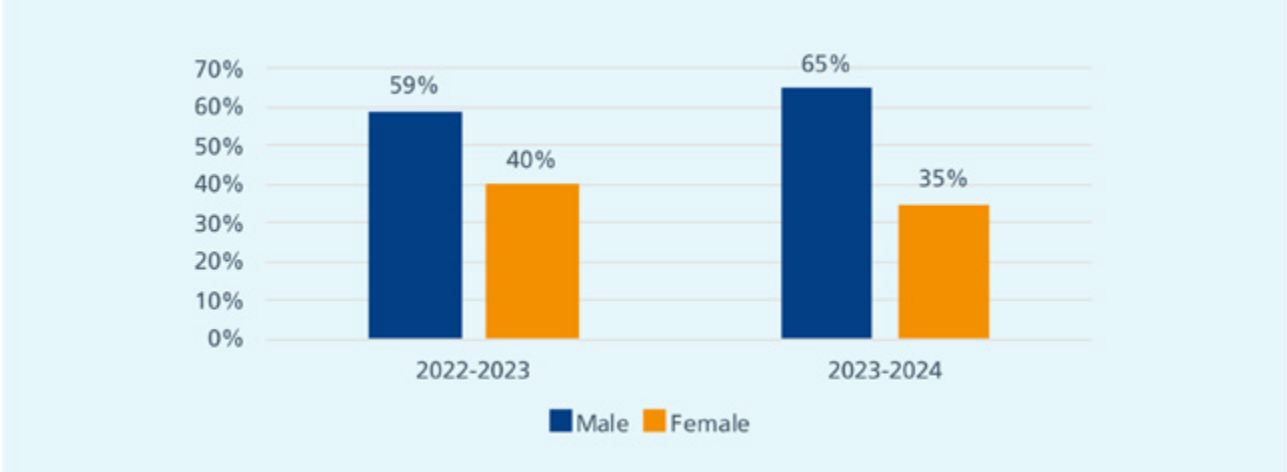
Figure 1.9 Median age of death



Gender

This year the data has shown a 5% decrease in the number of female deaths being notified to LeDeR. Of the 82 LeDeR notifications received males accounted for 65% of deaths and females 35%.

Figure 2.0 Gender



Ethnicity

We know that South East London is significantly more diverse than England however we continue to see under reporting to LeDeR from minority ethnic communities. Similar to the previous reporting year 70% of adults reported to LeDeR in 2023-2024 were of a white background. Figure 2.1 shows the ethnicity breakdown of the general population in South East London and figure 2.2 the ethnicity of the notifications received in 2023-2024. Please note the Office of National Statistics use a different ethnic breakdown when compared to LeDeR:

White	includes White British, Irish, Gypsy or Irish Traveller, and Other
Black	includes Black African, Caribbean, and Other
Asian	includes Indian, Pakistani, Bangladeshi, Chinese and Other
Mixed/ Other	includes White and Black Caribbean, White and Asian, White and Black African, Other Mixed, Arab and any Other ethnicity not covered above

Figure 2.1 Ethnicity – South East London general population

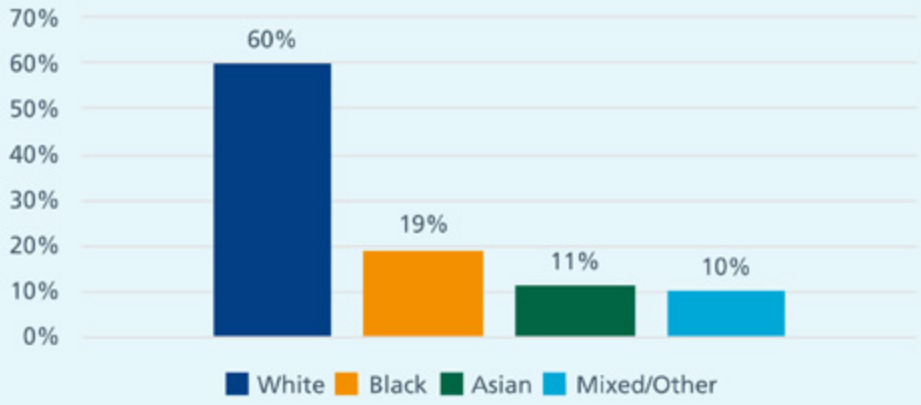
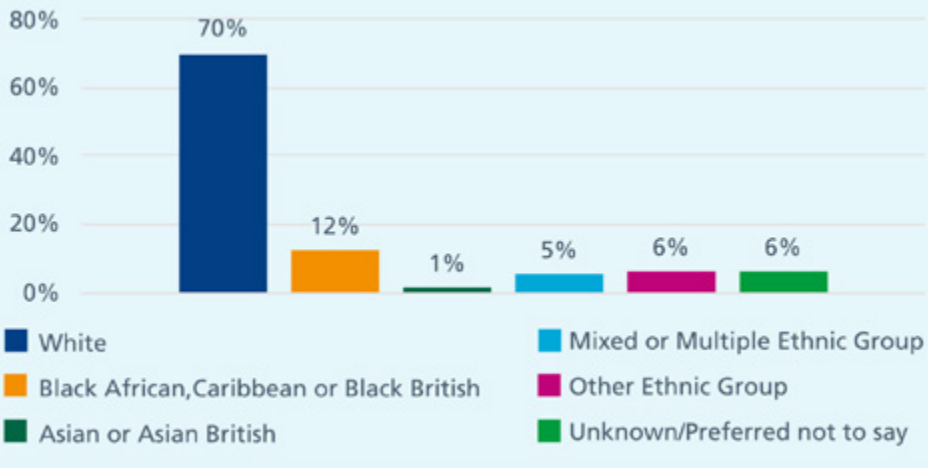


Figure 2.2 Ethnicity of LeDeR notifications received in 2023-2024



As an Integrated Care System, we will continue to work with our providers and stakeholders to promote and encourage more notifications for people from minority ethnic backgrounds, which will help us better understand the particular health inequalities and barriers these groups may face.

Figure 2.3 shows the ethnicity of the notifications received in each borough and figure 2.4 showing the ethnic breakdown for each South East London borough. Again, it highlights the significant under reporting of deaths of people with a learning disability and/or autism from minority ethnic communities.

Figure 2.3 Ethnicity of the LeDeR notifications received for each London borough 23-24

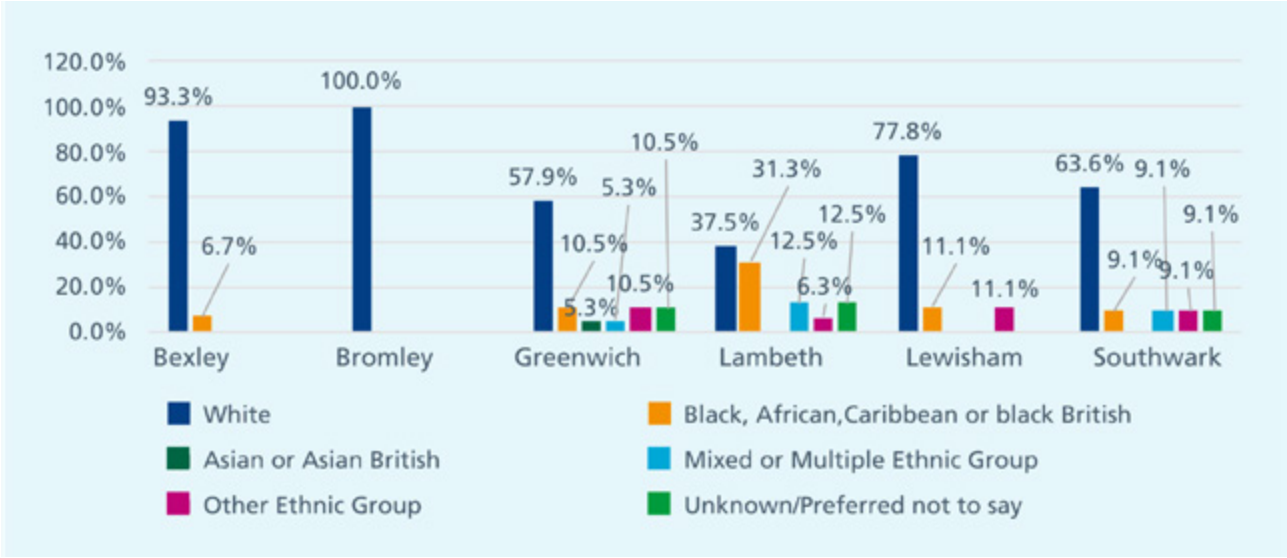
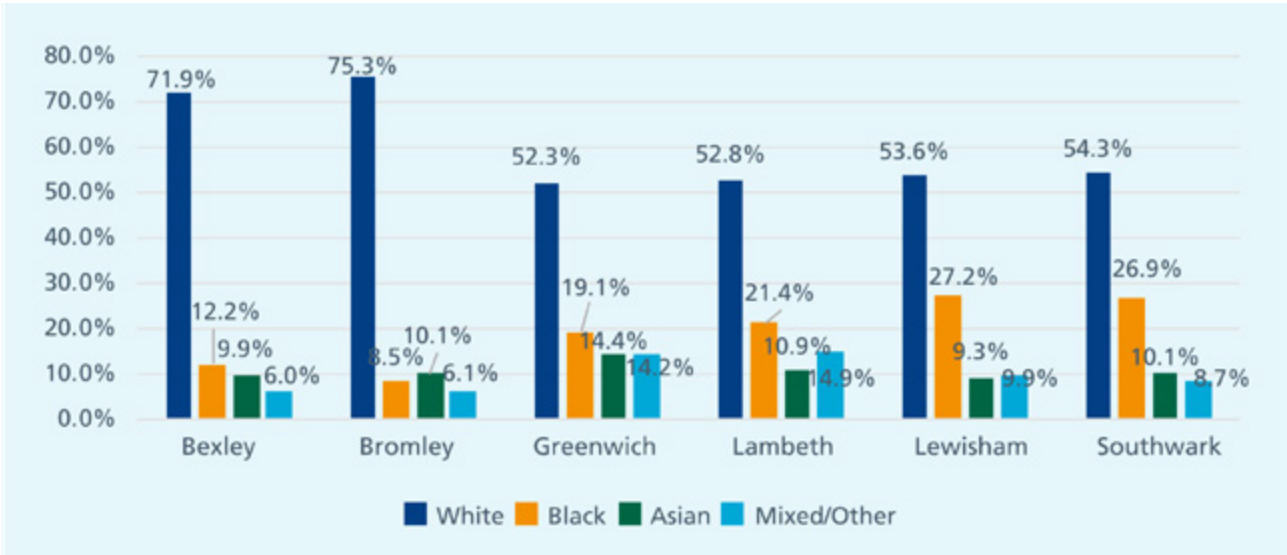


Figure 2.4 Ethnic breakdown of the general population.



Reviews completed in 2023-2024

Between April 2023 and March 2024, the SEL LeDeR team completed 54 LeDeR reviews, 30 initial and 24 focused. At the start of the reporting year, we faced a backlog of reviews so therefore commissioned an external provider Positive Support Group (PSG) to support the SEL LeDeR team in undertaking reviews. We worked closely with PSG to ensure reviews undertaken by them, were of a high quality.

Autism LeDeR Reviews

Like many other ICBs across London, the SEL LeDeR team have so far received very small numbers of notifications for autistic adults without a learning disability. In 2023-2024 we completed two focused reviews for autistic adults, only one more than in the previous year. To ensure confidentiality is maintained the analysis of our findings has not been included within this report. However, it is important to note that the current data reflects other research in highlighting the lack of understanding and acceptance of autism, diagnostic overshadowing, and lack of appropriate reasonable adjustments. This data will be maintained for purposes of learning within the ICS with a view to adding into future annual reports as the number of notifications and subsequent reviews increase and confidentiality of the individuals can be assured.

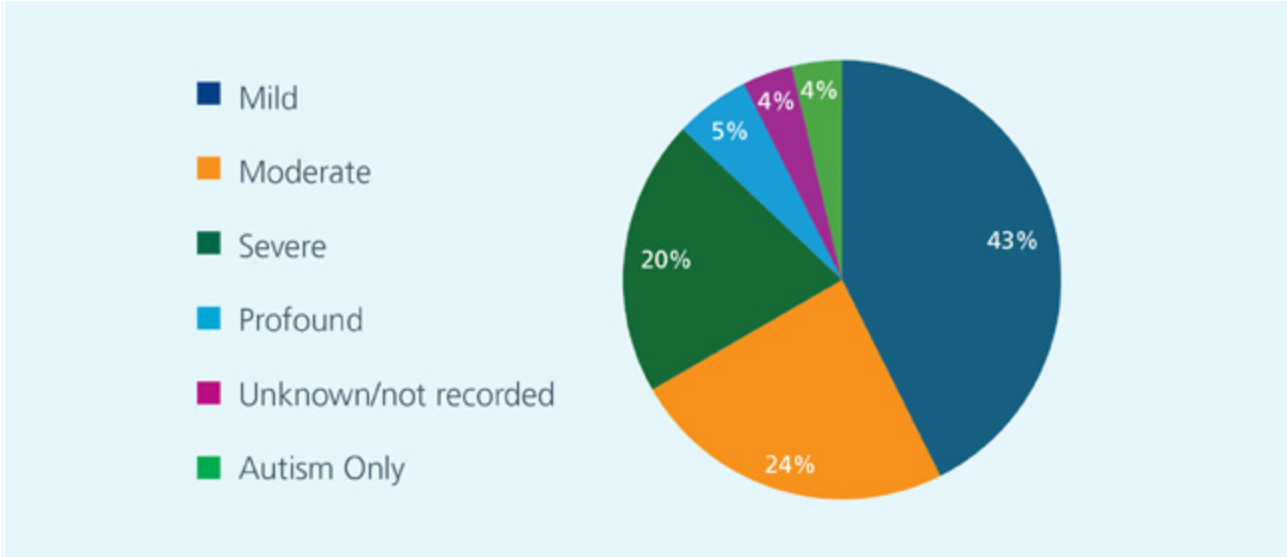
Although the number of LeDeR reviews conducted for autistic people without a learning disability was small and not representative of the population we can already see at this early-stage differences in comparison with autistic adults who have a learning disability, in particular who also have mental health conditions. We know that research has shown autistic people are more likely to experience poor mental health, and that autistic people are at a far greater risk of death from suicide than the general population.

All six South East London boroughs have or are working towards developing an All-Age Autism Strategy to ensure there is appropriate support and services in place to help autistic residents reach their full potential and live long and healthy lives. The SEL LeDeR team with the help from our stakeholders and providers, will continue to advocate and create awareness of the needs of autistic adults to ensure that autistic people have access to services that appropriately support their specific needs.

Level of Learning Disability

Of the 54 reviews completed, Figure 2.5 shows the level of learning disability recorded by the Reviewer.

Figure 2.5 Level of learning disability



Annual Health Checks/Learning Disability Register

Of the 54 LeDeR reviews completed 41 (76%) people had received an annual health check and 51 people (94%) were recorded as being on the GP Learning Disability Register. Table 1.1 shows the percentage of learning disability health checks completed in each London borough. All boroughs exceeded the annual target of 75%.

Table 1.1 Percentage of annual health checks completed (aged 14+) per borough in 23-24

Borough	LD Population	% with Annual Health Check
Bexley	1339	86.8%
Bromley	1386	79.2%
Greenwich	1855	92.0%
Lambeth	1857	91.0%
Lewisham	2234	93.4%
Southwark	1406	86.3%
SEL	10,077	

It was observed that for those that had an annual health check, there is a high prevalence of dysphagia (44%), gastrointestinal issues including constipation (51%), continence issues (46%), obesity (17%), mobility issues (61%), and end-of-life care issues (44%). The focus is then on the quality of annual health checks and whether service users were referred to appropriate services to minimise these risks. For example, we know dysphagia is one of multiple factors that may increase the risk of aspiration, constipation can lead to unnecessary hospital admissions, obesity adds increased risk for diabetes and cardiovascular diseases, mobility issues increase the risk of falls and fractures, and end-of-life care impacts quality of life.

We did not observe any meaningful correlations between various indicators such as location, ethnicity, and the likelihood of being offered an annual health check. However, this is due to the small data pool, which may not accurately reflect a statistically significant picture.

STOMP - Stopping over medication of people with a learning disability and autistic people

A third of the those offered an annual health check were on at least one psychotropic medication. However, the LeDeR review could not determine from the records seen if these medications were appropriately followed up on and reviewed by clinicians. Furthermore, a search in Primary Care involving 1,400 learning disability patients in South East London identified that a quarter of these patients are on at least one psychotropic medication without any mental health diagnosis. This aligns with our findings of a possible lack of awareness of STOMP from the collaborative training sessions and projects that have been delivered across South East London. The South East London Learning Disability and Autism Specialist Prescribing Team have completed a business case to implement a STOMP Clinic to support Primary Care across South East London. The STOMP clinics will be mobilised by quarter four 2024/2025.

Transition

Until the age of 18 services for children and young people are provided by child health and social care services. From 18 they are usually provided by adult services and will enter a period of transition. In 2023-2024 we received three notifications were the person who died was aged between 18 and 25. To maintain the confidentiality of these people it is not possible to go into detail about their reviews within this report.

Next of Kin involvement in the LeDeR review process

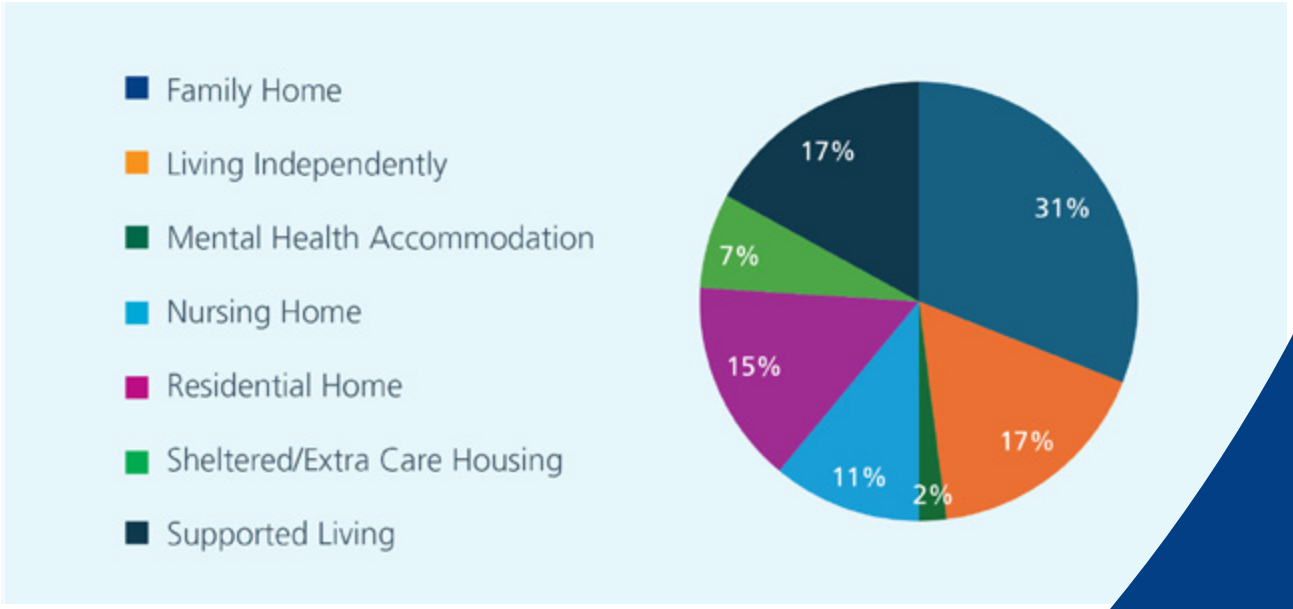
The LeDeR review process recognises the pivotal role played by carers and the importance of 'carer expertise,' in care provision. All families were offered an opportunity to participate and contribute to LeDeR reviews.

Of the 54 reviews completed, 29 had an identified next of kin involved in their care while 5 did not have a known next of kin. Conversations with the next of kin were mostly held with a sibling. Other relationships included parents, and extended family members. For the reviews where no next of kin was involved, the most common reason was difficulty making contact, even when contact information was available. Other reasons included the next of kin declining to participate due to grief or finding the process too upsetting, and cases where the person had no known or surviving next of kin.

Living arrangements of the people who died

31% of people with a learning disability and autism lived with their family.

Figure 2.6 Living arrangements



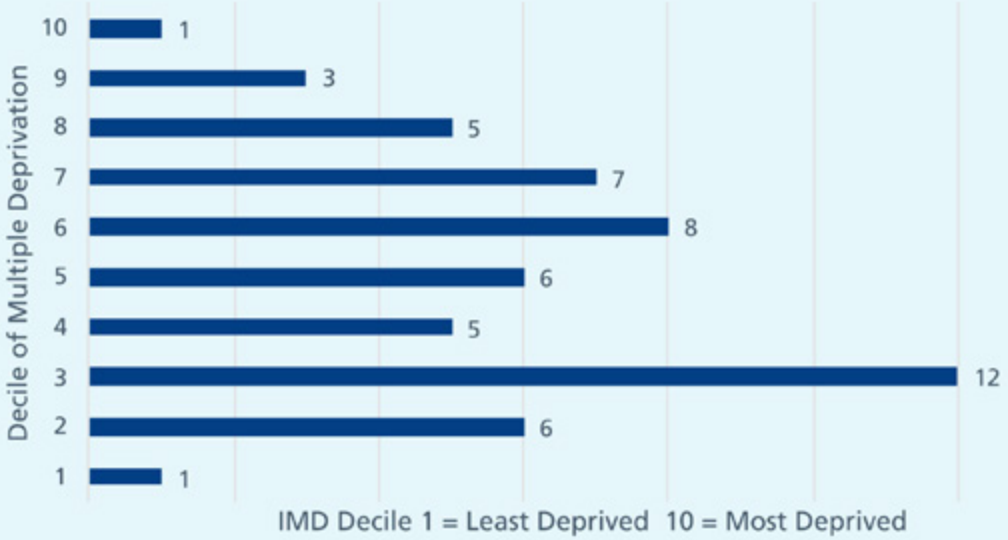
Index of Multiple Deprivation (IMD)

The Index of Multiple Deprivation (IMD) ranks each small area in England from the most deprived (Decile 1) to the least deprived (Decile 10) based on a combination of seven different factors including:

1. Income
2. Employment
3. Education
4. Health
5. Crime
6. Barriers to housing and services
7. Living environment

We know that evidence has shown that those living in the most deprived areas of England face the worst healthcare inequalities in relation to healthcare access, experience, and outcomes. Using the home postcode Figure 2.7 shows the IMD ranking for the 54 LeDeR reviews completed in 2023-2024. The average decile for the people we reviewed as 5, suggesting relatively low levels of deprivation across the various domains measured by the IMD for this cohort. The South East London LeDeR team will continue to collect and examine data in relation to IMD for future annual reports.

Figure 2.7 Completed reviews IMD ranking



Circumstances and Cause of Death

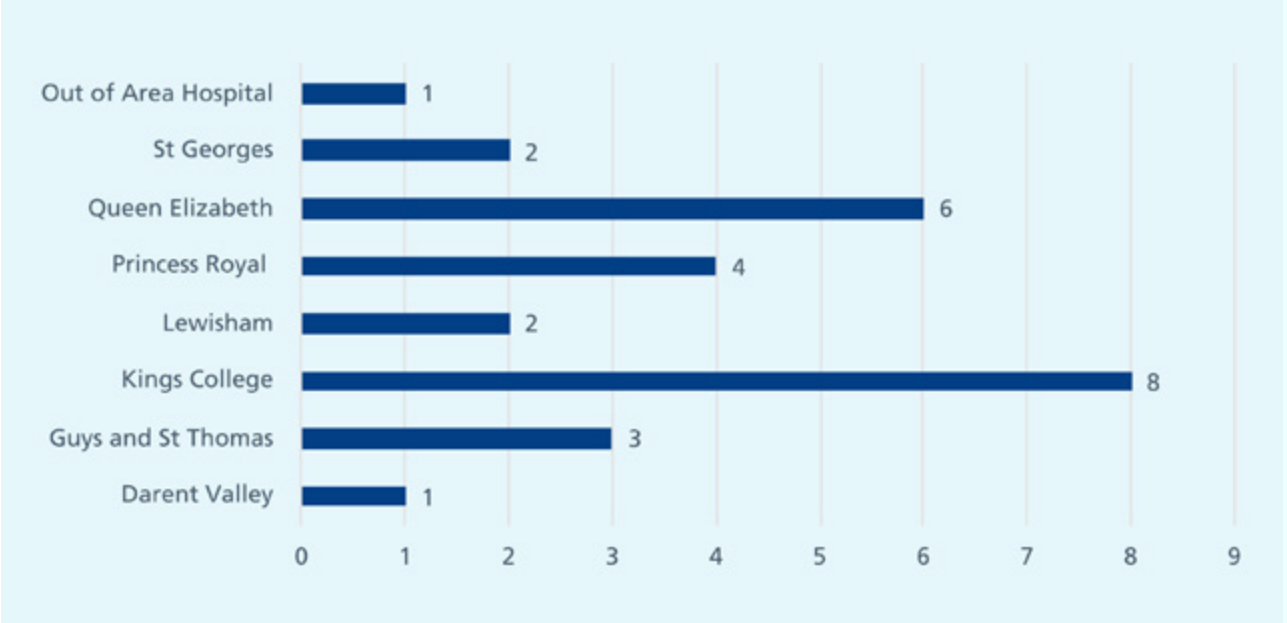
Place of death

Of the 54 reviews completed in 2023-2024 half (50%) of all deaths occurred in hospital. In 2023-2024 we saw less deaths occurring at home and more deaths within a hospice setting. For hospital deaths Figure 2.8 shows the breakdown of hospitals.

Table 1.2 Place of death

Place	2022-2023	2023-2024
Hospital	51%	50%
Usual Place of Residence	41%	35%
Hospice	4%	9%
Other	3%	4%
Mental Health Unit	1%	2%

Figure 2.8 Hospital deaths



Cause of death – South East London

Table 1.3 shows the most common cause of death for people whose LeDeR review was completed between April 2023 and March 2024. Whilst pneumonia, cancer and sepsis have remained in the top five we had no reported Covid-19 deaths. We also want to understand more about how the main causes of death identified from LeDeR reviews differs from the general population and will look at this in more detail for our 2024-2025 annual report.

It was noted by Reviewers that some of the death certificates stated learning disability as a cause of death. Learning disability can be listed in Part 2 of the death certificate if thought to be a contributory factor, but not in Part 1, as having a learning disability does not form a direct sequence of events leading to a person's death. It's anticipated with the advent of Statutory Medical Examiner scrutiny for all deaths, these instances will decrease.

Table 1.3 Cause of death

Cause of death – South East London	Percentage
Pneumonia (Aspiration and Bronchopneumonia)	31%
Cancer	15%
Sepsis (including E.Coli and chest sepsis)	9%
Kidney Disease	9%
Gastrointestinal haemorrhage (including Duodenal & Oesophageal Ulcer)	9%
Ischaemic Heart Disease	7%
Chest Infection	7%
Pulmonary Embolism	4%
Sudden Unexpected Death in Epilepsy (SUDEP)	4%
Brain Haemorrhage	4%
Chronic Obstructive Pulmonary Disease (COPD)	4%
Complications of post-meningitis severe brain injury	2%
Frailty	2%
Cardiac Arrest	2%
Immersion	2%
Peritonitis	2%
Alzheimer's	2%

Deaths reported to Coroner

Deaths are reported to a coroner in certain circumstances. These can include suspicious deaths, those with an unknown cause, or deaths which have occurred under state detention. It is important to note that a death reported to a coroner is not an indication of the quality of care a person received. Of the 54 reviews completed 14 were referred to the coroner.

Deaths with DNACPR

A do not attempt cardiopulmonary resuscitation (DNACPR) decision is put in place to protect people from unnecessary suffering by receiving cardiopulmonary resuscitation (CPR) that they don't want, that won't work or where the harm to them outweighs the benefits. According to the National Institute for Health and Care Excellence (NICE) guidelines, DNACPR decision must be made on an individual basis. Of the 54 LeDeR reviews completed 23 (43%) people had a DNACPR in place at the time of death, 19 of these were discussed with a family member.

End of Life Care

A good End-of-Life care plan should include priorities and preferences for care and treatment, decisions about resuscitation, views about how and where they would like to be looked after in their last days of life, who they would like to have with them and any spiritual or religious beliefs they would like to be considered. 24 reviews completed had an End-of-Life care plan in place. Eight died in their usual residence, twelve died in hospital and four died in a hospice. The most common long-term conditions that people who received end of life care had included dysphagia (12), cancer (10), continence problems (14), mobility problems (15), sensory impairment (12), epilepsy (12) and gastrointestinal disorders (11). Of the twenty-four people who received end of life care, seventeen of these had DNACPR in place.

Cause of death – by borough

In four out of the six London boroughs (Bexley, Bromley, Greenwich, and Lambeth) pneumonia was the leading cause of death. In Lewisham, the leading cause of death was respiratory illnesses such as COPD and Southwark cancer. Bromley and Southwark both had the highest number of cancer related deaths and Lewisham was the only borough to not have any reported deaths by sepsis.
All boroughs except Greenwich and Bromley reported deaths linked to gastrointestinal conditions.

Cause of death – by age group

Table 1.4 shows the main cause of death by each age group. Whilst pneumonia continues to be the main cause of death across all age groups, sudden unexpected death in epilepsy (SUDEP) was only seen in age group 25-49 and sepsis more prevalent in age group 65+.

Table 1.4 Cause of death by age group

Reported Sex (Registered at birth)	Age group at death (years) 18-24	25-49	50-64	65+
Male	1	5	13	13
Female	2	5	7	8
Total	3	10	20	21
Main causes of death within age group	Respiratory conditions including Pneumonia	Pneumonia and sudden unexpected death in Epilepsy (SUDEP)	Pneumonia and Cancer	Sepsis, Cancer, and Pneumonia

Cause of death – Pneumonia

Respiratory disease, particularly bronchopneumonia, is a leading cause of death in people with learning disabilities, in particular in those with profound and multiple disabilities, accounting for significantly more deaths than in the local general population[1] [2].

In 2021, the Scottish Learning Disabilities Observatory[3] stated that risk of death from respiratory disease is 6.5 times greater and risk of death from pneumonia is 27 times greater in adults with learning disabilities compared to the general population.

Risk factors for people with learning disabilities in developing pneumonia or serious chest infections include:

- Compromised or vulnerable respiratory status.
- Poor recognition/management of acute and chronic respiratory conditions.
- Reduced mobility, poor posture, and positioning.
- Poor oral care/oral microbial load.
- Poorly controlled epilepsy and/or medication side effects.
- Unrecognised/poorly managed gastroesophageal disease (GORD)/laryngopharyngeal reflux disease (LPRD).
- Lack of recognition of sleep disordered breathing.

Poor oral health and hygiene

Poor oral care is a known risk factor for developing community acquired pneumonia. LeDeR reviews do not collate specific information regarding oral and dental care. However, national, and international research, including systematic reviews[4], consistently shows that people with learning disabilities have:

- Higher levels of gum (periodontal) disease.
- Greater gingival inflammation.
- Higher numbers of missing teeth.
- Increased rates of toothlessness (edentulism).
- Higher plaque levels.
- Greater unmet oral health needs.
- Poorer access to dental services and less preventative dentistry.

In 2023 the British Thoracic Society (BTS) produced a Clinical Statement[5] on the prevention and management of community-acquired pneumonia in people with learning disability, they state: "prevention, early detection and proactive management are key to reducing mortality from avoidable causes". They identified the need for complete history taking and review of systems and clinical examination. See appendix 1.

As a team we are going to look closer at oral health and how this impacts the health of those with a learning disability and autistic people, our findings will be analysed and included as part of our 2024-2025 annual report.

Long Term Health Conditions

When a death is reviewed by a LeDeR Reviewer, information is collected about whether the person had any long-term health conditions. From the 54 LeDeR reviews completed in 2023-2024 table 1.5 shows comparable data to the previous year with mobility difficulties remaining the most recorded long-term condition. 61% were known to have mobility difficulties or at risk of falls which means support with activities of daily living, appointments, accessing services but also provision of appropriate reasonable adjustments would have been important.

Table 1.5 Long-term health conditions

Long Term Health Conditions	Percentage
Mobility Difficulties (Including mobility aids and frequent falls)	61%
Continence Problems (Including Urinary Tract Infection (UTI) and Incontinence)	50%
Gastro-intestinal Problems (Including Constipation)	48%
Dysphagia	41%
Epilepsy	39%
Sensory Difficulties	33%
Cancer	28%
Mental Health Condition	28%
Asthma/Chronic Obstructive Pulmonary Disease (COPD)	24%
Cardiovascular Disease (excluding Hypertension/Stroke)	26%
Hypertension	26%
Chronic Kidney Disease (Renal)	26%
Diabetes	20%
Body Mass Index (BMI) over 30	17%
Dementia	15%
Stroke	9%
Deep Vein Thrombosis (DVT)	4%
Body Mass Index (BMI) Under 18	2%

All 54 LeDeR reviews completed recorded the person as having 2 or more long term health conditions, including physical health and/or psychological conditions. These findings will be shared at our South East London ICS LeDeR Strategic Group meeting and other key governance meetings to help us systematically identify how we can link in with

specific teams such as frailty and continence to ensure people with a learning disability and autistic people are getting the right support to manage their long-term conditions. Table 1.6 shows the number of long-term conditions recorded within the review broken down into each of the six boroughs. As the number of reviews completed in each borough is different comparisons of the prevalence of each long-term condition should be interpreted with caution. A larger analysis of epilepsy, cancer, mental health, and dysphagia can be found below.

Table 1.6 Long-term health conditions recorded by borough

Long Term Health Conditions	Bexley	Bromley	Greenwich	Lambeth	Lewisham	Southwark
Mobility Difficulties (Including mobility aids and frequent falls)	6	6	4	6	4	6
Continence Problems (Including Urinary Tract Infection (UTI) and Incontinence)	5	5	3	4	3	6
Gastro-intestinal Problems (Including Constipation)	6	4	2	5	2	6
Dysphagia	7	1	4	4	2	3
Epilepsy	5	4	3	3	2	3
Sensory Difficulties	6	3	3	3	0	2
Cancer	2	5	2	1	1	4
Mental Health Condition	3	1	2	1	5	2
Asthma/Chronic Obstructive Pulmonary Disease (COPD)	3	2	1	1	3	2
Cardiovascular Disease (excluding Hypertension/ Stroke)	2	0	4	1	3	4
Hypertension	1	1	2	4	4	1
Chronic Kidney Disease (Renal)	3	3	1	3	2	2
Diabetes	1	1	0	3	3	4
Body Mass Index (BMI) over 30	1	4	1	0	3	0
Dementia	1	0	2	1	2	2
Stroke	2	1	0	1	0	1
Deep Vein Thrombosis (DVT)	0	1	0	0	1	0
Body Mass Index (BMI) Under 18	0	0	1	0	0	0

Long Term Health Condition - Epilepsy

Epilepsy is one of the most prevalent neurological conditions that affects over 70 million people in the world. In the United Kingdom, the prevalence of epilepsy is between 5-10 cases per 1000 people. Epilepsy is more prevalent in people with a learning disability, with an increase in incidence in people with a severe and profound learning disability. One per cent of the general population have epilepsy, compared to 20% of those with a learning disability. Out of the 54 reviews completed in 2023-2024, 21 people had a diagnosis of epilepsy, of which 12 had a severe or profound learning disability. For those that had a diagnosis of Epilepsy the average age of death was found to be 49 years.

The highest cause of death for epilepsy related LeDeR reviews was pneumonia (Aspiration and Bronchopneumonia) at 43%. 19% were due to cancer and 9% (2 reviews) were due to sudden unexpected deaths in epilepsy (SUDEP).

Figure 2.9 Epilepsy – level of learning disability

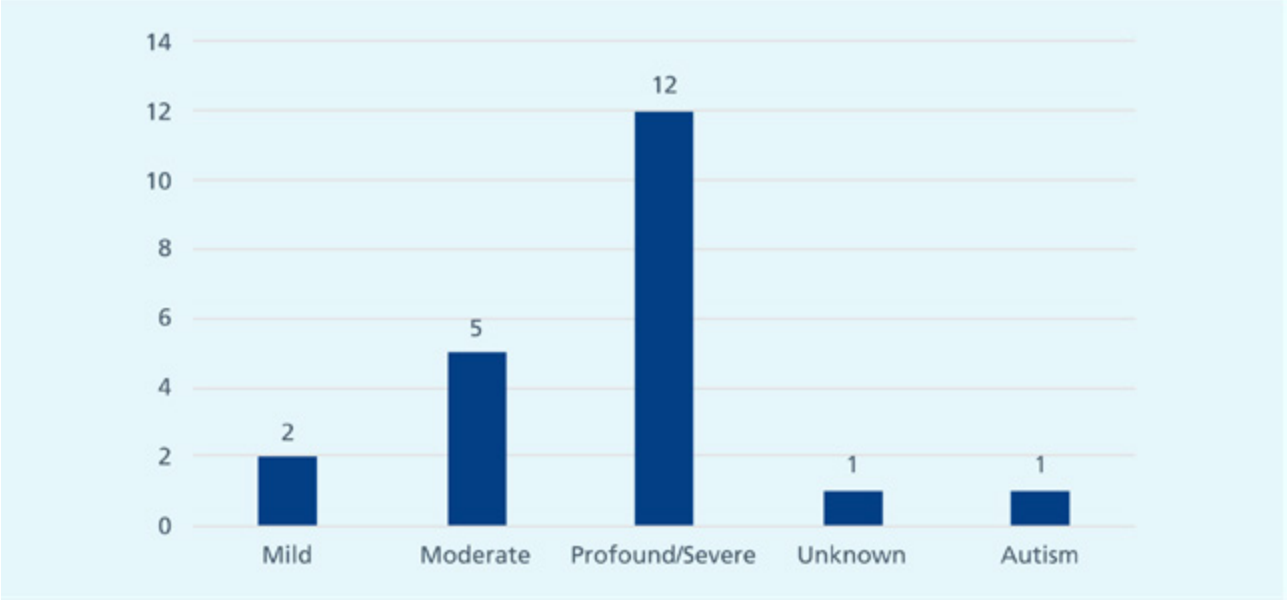
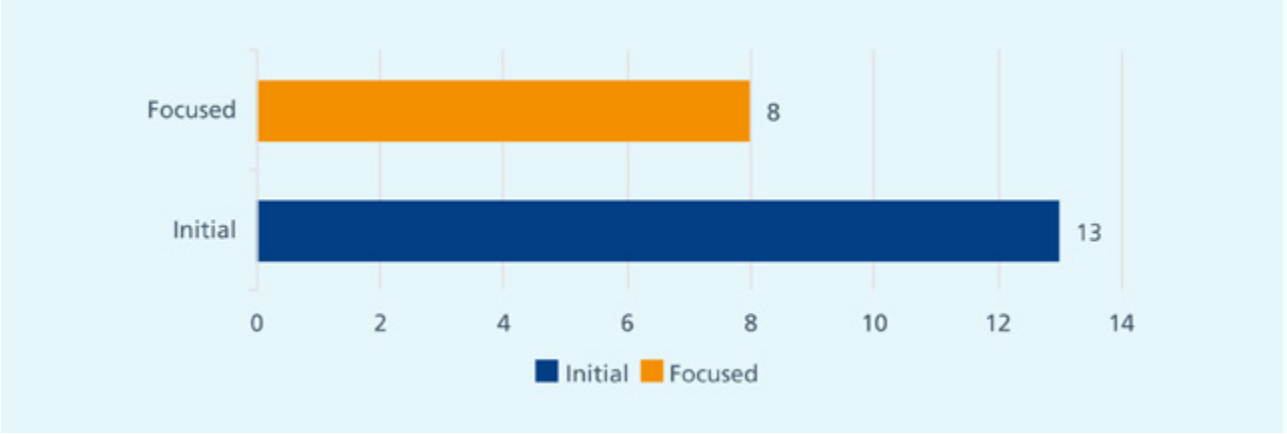


Figure 3.0 Type of review - epilepsy

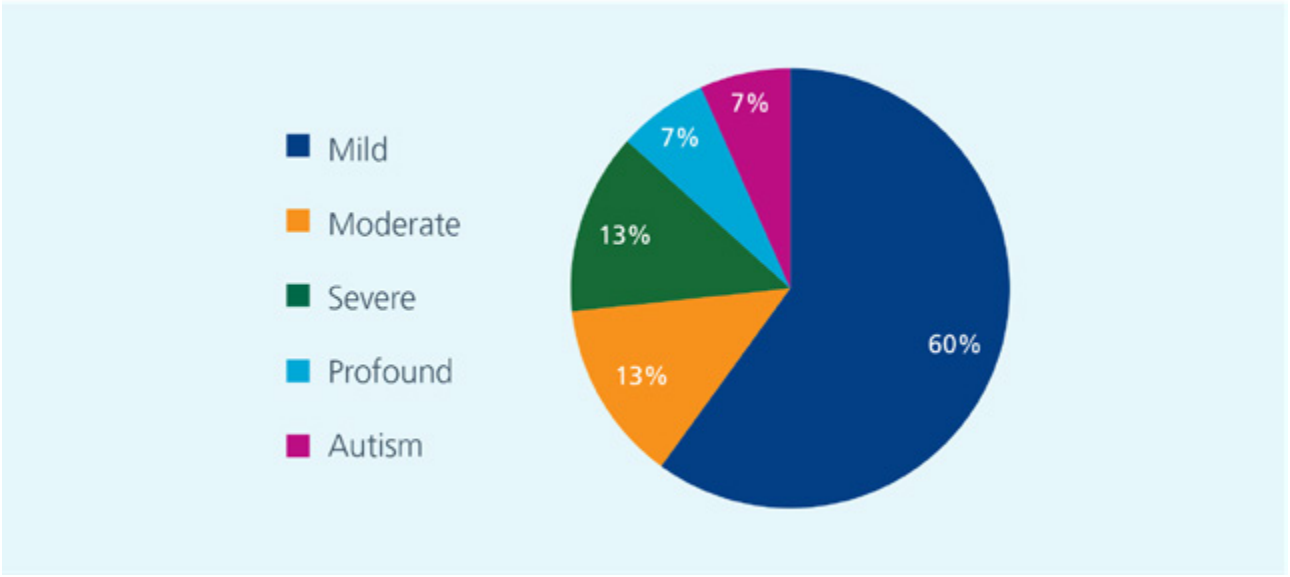


Long Term Health Condition - Cancer

Of the 54 LeDeR reviews completed, fifteen were recorded as having cancer as a long-term health condition. Out of the fifteen reviews, nine reviews were found to have cancer indicated as the cause of death, this included cancers such as gallbladder, lung, pancreas, jaw, B cell lymphoma and colon. The highest number of those that died from cancer had a mild learning disability.

In England we currently have national cancer screening programmes for cervical, breast and bowel cancer. Cancer screening is an example of secondary prevention, as it can detect signs of cancer in people before any symptoms appear. Early detection is important because it increases the chances of successful treatment and survival. Ensuring that screening is accessible to people with a learning disability and autistic people is especially important as they are more likely to encounter difficulties recognising and communicating symptoms of possible cancer, which can increase the risk of a delayed diagnosis. In addition to the screening programmes annual health checks also play a vital role in spotting any changes/symptoms in someone's physical health. Of the fifteen reviews completed who had cancer, ten people had received an annual health check within the last 12 months of their life. For the five that did not receive an annual health it was not clear from the records seen if this was not offered or offered and declined.

Figure 3.1 Cancer diagnosis – level of learning disability



During quarter 4 of the reporting year 2023-2024 our local area of focus for LeDeR was cancer. We converted all cancer related LeDeR reviews within this quarter into a focused review. It is hoped by converting these reviews we can gain a better understanding of cancer screening and diagnosis/treatment across South East London. This data will be analysed and shared in our 2024-2025 annual report.

Long Term Condition - Mental Health

Adults with learning disabilities in the UK experience significantly higher rates of mental health difficulties compared to the general population. According to the Mental Health Foundation approximately 54% of adults with learning disabilities have a mental health problem. In contrast, the general population has a lower prevalence, with around 17.2% experiencing common mental health problems.

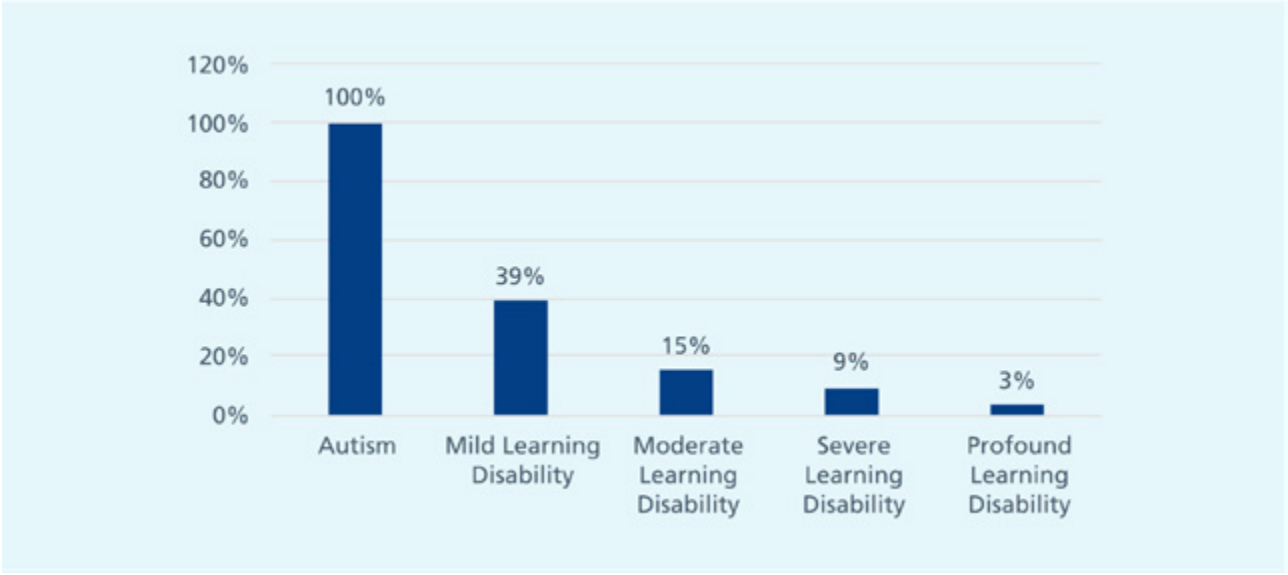
Adults with learning disabilities are more likely to experience mental health issues such as anxiety, depression, and schizophrenia compared to those without learning disabilities[6]. For example, the prevalence of psychiatric illness in people with learning disabilities is around 32.2%, compared to 11.2% in the general population[7].

Autistic individuals in the UK also face significantly higher rates of mental health difficulties compared to the general population. Autistic individuals are believed to be at a higher risk of suicidal thoughts and behaviours compared to the general population. Cassidy et al[8] in their analysis of 372 coroners' inquest records from two regions of England conclude that "elevated autistic traits are significantly over-represented in those who die by suicide".

The overall prevalence of any psychiatric diagnosis in autistic adults ranges from 15.4% to 79%, depending on various factors such as age and diagnostic methods[9].

Twenty-eight per cent of all people reviewed by South East London LeDeR had a co-occurring mental health condition. The chart below shows the percentage of each level of learning disability and autistic individuals who were reported to have a mental health condition. It should be noted that less than 5 of the people we reviewed had a diagnosis of autism, therefore we cannot assume statistical significance. No one had suicide as a cause of death.

Figure 3.2 Mental health – level of learning disability



Long Term Condition – Dysphagia

Dysphagia is the medical term for swallowing difficulties. The Royal College of Speech and Language Therapists (RCSLT, 2023)[10] states: individuals with a learning disability have a greater risk of dysphagia leading to:

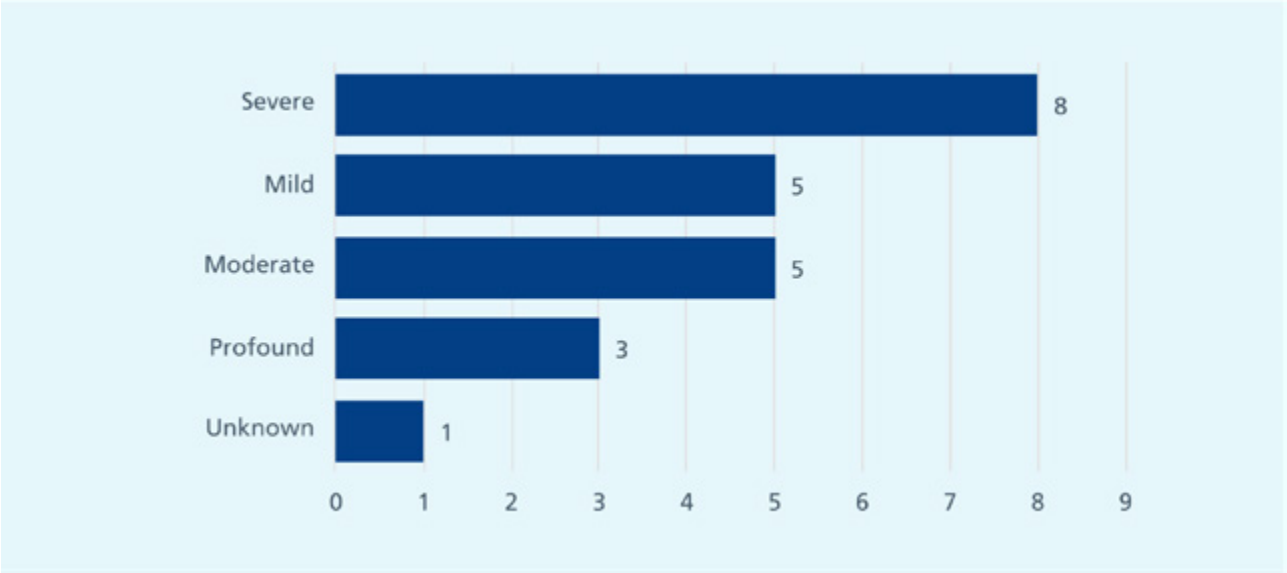
- Discomfort/reduced mealtime enjoyment.
- Malnutrition and dehydration.
- Aspiration, leading to poor respiratory health and chest infections.
- Choking (asphyxiation/airway blockage), potentially leading to death.

According to RCSLT (2023) "8% of people with learning disabilities, known to health and social care services, will have dysphagia, and 15% will require support to eat and drink" (Public Health England[11], 2016). Dysphagia may contribute the high rates of hospitalisation and death from aspiration pneumonia, as well as being associated with risk of sudden death from choking and in malnutrition in people with a learning disability who are underweight" (NHS Digital, 2016[12]).

However, dysphagia is not an independent predictor of aspiration. Dysphagia is one of multiple factors that may increase risk of respiratory infection/aspiration pneumonia in people with a learning disability.

In South East London, 22 of the 54 people reviewed (41%) in 2023-2024 by LeDeR had a diagnosis of dysphagia. Dysphagia is generally more common in people with more severe learning disabilities, in people with learning disabilities who have cerebral palsy, and is also associated with motor impairment.[13]

Figure 3.3 Severity of the individual's learning disability



The greatest number of people with dysphagia who died had a severe level of learning disability (36%), people with a mild and moderate learning disability were equal at 23%, however those with the highest level of need, those with a profound learning disability, equated to 14% of those who died. Dysphagia is not a cause of death in itself, and these figures are purely descriptive of the cohort of people we reviewed in South East London.

Dementia

Five of those people reviewed by South East London LeDeR, who had dysphagia, also had dementia. Most people living with dementia go on to develop eating, drinking and swallowing difficulties. For people with learning disabilities this can be further complicated by pre-existing difficulties and long-term conditions. Different dementias differ substantially in their impact on swallowing and in the timing of this.

Epilepsy

Although RCSLT does not explicitly mention epilepsy as an additional risk factor, there is a risk of developing dysphagia in individuals with epilepsy which can be influenced by several factors, including the severity and frequency of seizures, the type of epilepsy, and the medications used for treatment. In South East London 20 people with a learning disability had epilepsy, and 12 of those had dysphagia. While specific statistics for the UK are not readily available, some general insights are:

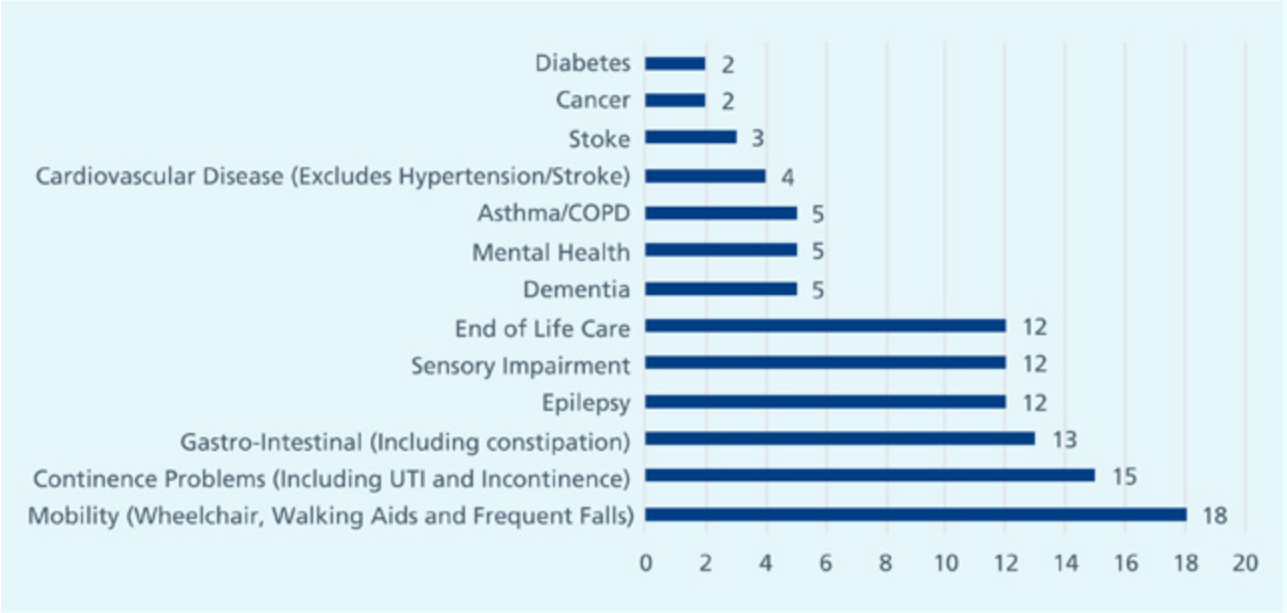
1. **Seizure Activity:** Frequent or severe seizures can increase the risk of dysphagia. This is because seizures can affect the muscles and nerves involved in swallowing. Seizure activity can also affect arousal levels, making it more risky to eat and drink.
2. **Medications:** Certain antiepileptic drugs (AEDs) may have side effects that impact swallowing. For example, some medications can cause dry mouth, affect muscle coordination, or cause drowsiness.
3. **Neurological deterioration:** Further brain damage can be caused by seizure activity.

Other risk factors:

- Poor oral health and hygiene – see cause of death – pneumonia.
- Individual's eating practice.
- Requirement for physical mealtime support.

We do not currently collate information on these three additional factors as part of our LeDeR reviews.

Figure 3.4 Dysphagia and co-morbidities



Cause of Death

As has been discussed elsewhere in this report, respiratory disease, particularly bronchopneumonia, is a leading cause of death in people with learning disabilities [14 15]. Not all the people with dysphagia reviewed by LeDeR died because of a respiratory condition, but the majority (59%) did; of which 23% had a chest infection or lower respiratory tract infection, and the remaining 77% had pneumonia listed as cause of death. This does not prove causation but suggests dysphagia may correlate and interact with other risk factors and co-morbidities to heighten the risk of pneumonia or chest infection.

Ethnic Minority Communities

Of the 54 reviews completed 15 reviews were recorded as being from an ethnic minority community. As per the 2021 LeDeR policy, all were completed as focused reviews. The median age at death for those with a learning disability and or autism is 50 years when compared to the white population which is 62 years. Figure 3.5 shows how many ethnic minority reviews were completed for each borough and figure 3.6 showing the breakdown of ethnicity

Figure 3.5 Ethnic Minority Communities - reviews completed per borough

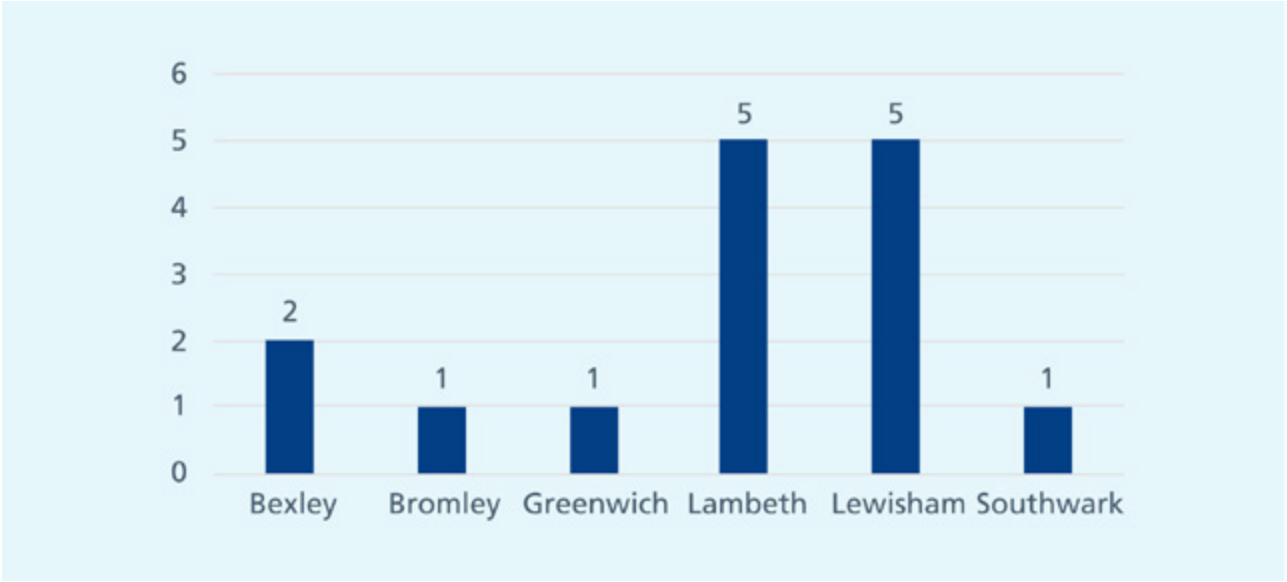
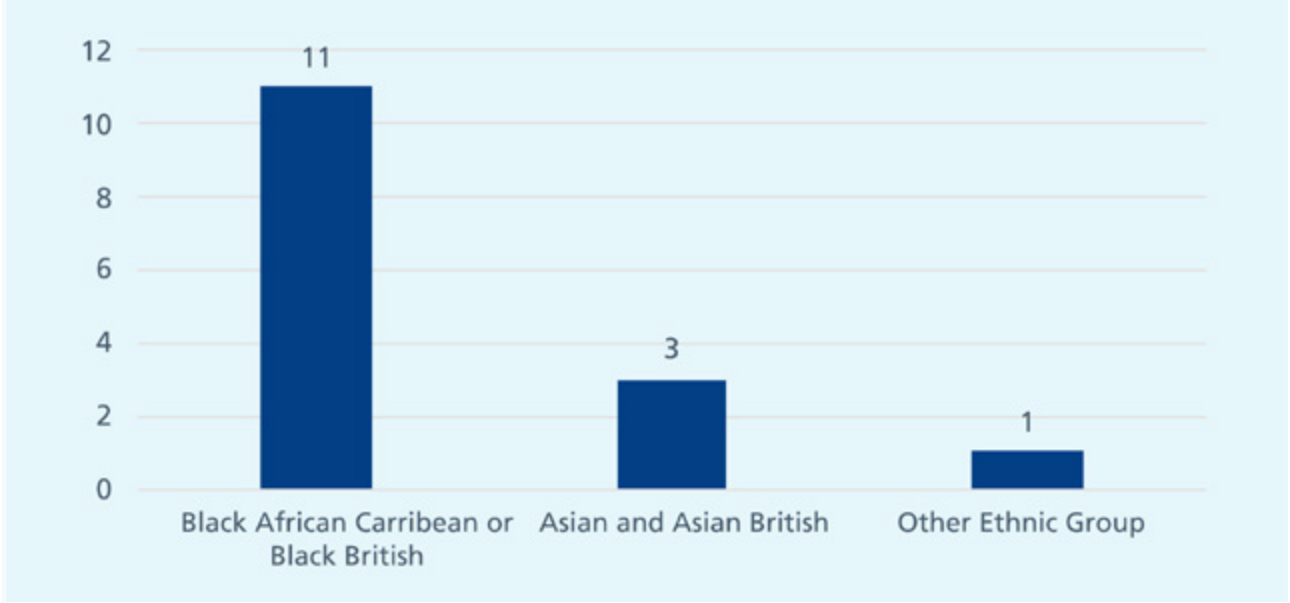


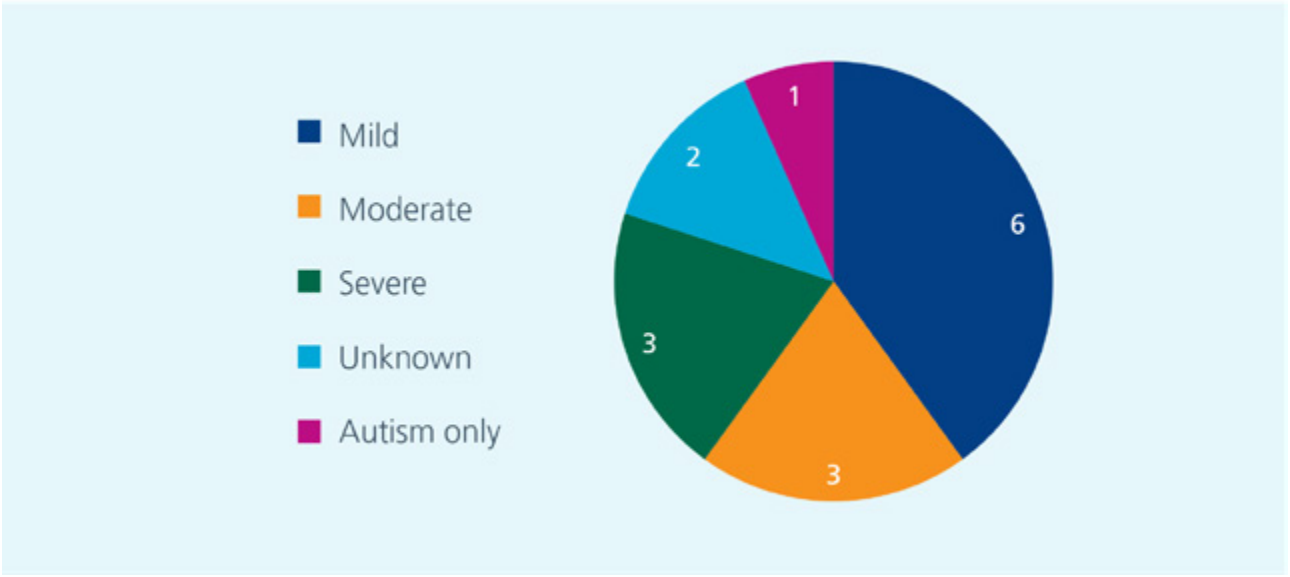
Figure 3.6 Ethnic Minority Communities – ethnicity



Ethnic Minority Communities - Level of learning disability

Of the 15 reviews completed 14 had a diagnosis of learning disability and one autism only. Figure 3.7 shows the level of learning disability recorded by the Reviewer.

Figure 3.7 Ethnic Minority Communities - level of learning disability



Ethnic Minority Communities - Cause of death

The cause of death within the ethnic minority community was found to be similar when compared to the white population with pneumonia being the most recorded cause of death.

Table 1.7 Ethnic Minority Communities - cause of death

Cause of death	Number
Pneumonia; including Aspiration, Broncho and Pneumococcal	3
Sepsis	2
Heart Disease; including cardiac conditions	2
Multi-Organ Failure	2
Respiratory Failure	1
Pulmonary Embolism	1
Cancer/Lymphoblastic Leukaemia	1
Sudden death from epilepsy - SUDEP	1
Immersion	1
Gastro-Intestinal Haemorrhage	1

Ethnic Minority Communities - Annual Health Checks & Learning Disability Register

67% had received an annual health check and 93% were on the learning disability register.

Ethnic Minority Communities - Deaths with DNACPR

From the reviews completed in 2023-2024, 23 people had a DNACPR in place at the time of death. Of these 23, twenty (87%) were recorded as white and three (13%) from an ethnic minority background. In order to understand this disparity an in-depth analysis will be completed and fed back in future reports.

Ethnic Minority Communities - Long Term Health Conditions

Mobility difficulties were found to be the most prevalent long-term health condition in both white and ethnic minority communities. However, it was noted that, people from an ethnic minority background had a higher percentage of gastro-intestinal problems and mental health conditions.

Table 1.8 Ethnic Minority Communities - long term health conditions

Ethnic Minority Communities: Long Term Health Conditions	Percentage
Mobility difficulties (Including mobility aids and frequent falls)	60%
Gastro-intestinal Problems (Including Constipation)	60%
Continence Problems (Including Urinary Tract Infection (UTI) and Incontinence)	47%
Mental Health Condition	40%
Dysphagia	40%
Epilepsy	33%
Sensory difficulties	27%
Chronic Kidney Disease (Renal)	27%
Asthma/Chronic Obstructive Pulmonary Disease (COPD)	27%
Hypertension	27%
Diabetes	20%
Cardiovascular Disease (excluding Hypertension/Stroke)	20%
Body Mass Index (BMI) over 30	20%
Cancer	13%
Dementia	7%
Body Mass Index (BMI) Under 18	7%
Stroke	7%
Deep Vein Thrombosis (DVT)	0%

Quality of Care and Responsiveness of ICS Services: Focused Reviews

24 focused reviews were completed within 2023-2024. The focused reviews completed have an additional question which requires the reviewer to grade both the quality of care and responsiveness of the ICS services the person received. This is rated on a six-point scale as shown below. 29% of the completed focused reviews received good care with responsiveness of ICS services being good and meeting the expected standard for 17% of reviews. We recognise what this means for care delivered to people with learning disability and autistic people in South East London. Actions to address this will be identified at the South East London ICS Strategic Group. Resulting actions and the impact on care delivery will be reported in the 2024-2025 South East London LeDeR report.

Table 1.9 Quality of care grading

Grade	Quality of Care	Number	Percentage
1	Care fell far short of expected good practice and this contributed to the cause of death.	0	0%
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.	6	25%
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.	7	29%
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).	4	17%
5	This was good care (it met expected good practice).	7	29%
6	This was excellent care (it exceeded expected good practice).	0	0

Table 2.0 Focused reviews - Grading of quality of care versus severity of learning disability

Grading	Mild	Moderate	Severe	Profound	Unknown	Total
1	0	0	0	0	0	0
2	3	1	1	0	0	4
3	3	1	1	1	1	6
4	3	0	0	0	1	4
5	2	2	2	0	0	6
6	0	0	0	0	0	0

Table 2.1 Responsiveness of ICS services

Grade		Number	Percentage
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.	0	0%
2	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.	5	21%
3	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.	9	37%
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.	6	25%
5	Responsiveness of ICS services to the person's needs was good and met the expected standard.	4	17%
6	Responsiveness of ICS services to the person's needs was excellent and exceeded the expected standard.	0	0%

We will be undertaking further work to correlate the recurring themes and pathways that are detrimentally impacting on responsiveness of ICS services, as the overwhelming majority fell short of the expected standard, and in a fifth of those people reviewed, this shortfall had the potential to contribute to cause of death.

Table 2.2 Grading of responsiveness of ICS services versus severity of learning disability

Grading	Mild	Moderate	Severe	Profound	Unknown	Total
1	0	0	0	0	0	0
2	3	1	1	0	0	5
3	3	1	1	1	2	8
4	3	1	2	0	0	6
5	2	1	0	0	0	3
6	0	0	0	0	0	0

Care Packages

In six out of the twenty-four focused reviews completed (25%), reviewers reported that, from the available evidence, the care package in place at the time of death did not meet the needs of the person who died. For four of these people, there were also concerns about the quality of the care received. Two of these people were living in the family home and two were living independently in the community. Reasons for the care package not meeting the needs of the person included:

- Not enough carer hours to provide support for basic tasks of daily living, including personal care.
- Difficulties in sourcing appropriate placements that could meet the needs of the person, for example, nursing care.
- Family members' turning down increased levels of support. In these situations, there was no evidence that a mental capacity assessment had been conducted to establish if the person themselves were able to consent to how their care needs were met.
- The person themselves not engaging with support, again, in these situations, there was no evidence that mental capacity assessments had been completed to establish if the person was able to make decisions about their care and support needs.

Care Concerns

There were concerns in fourteen of the twenty-four focused reviews completed (58%). Of these, two cases went on to be referred to the SAR process because of the LeDeR review.

Figure 3.8 Number of focused reviews in each borough with care concerns

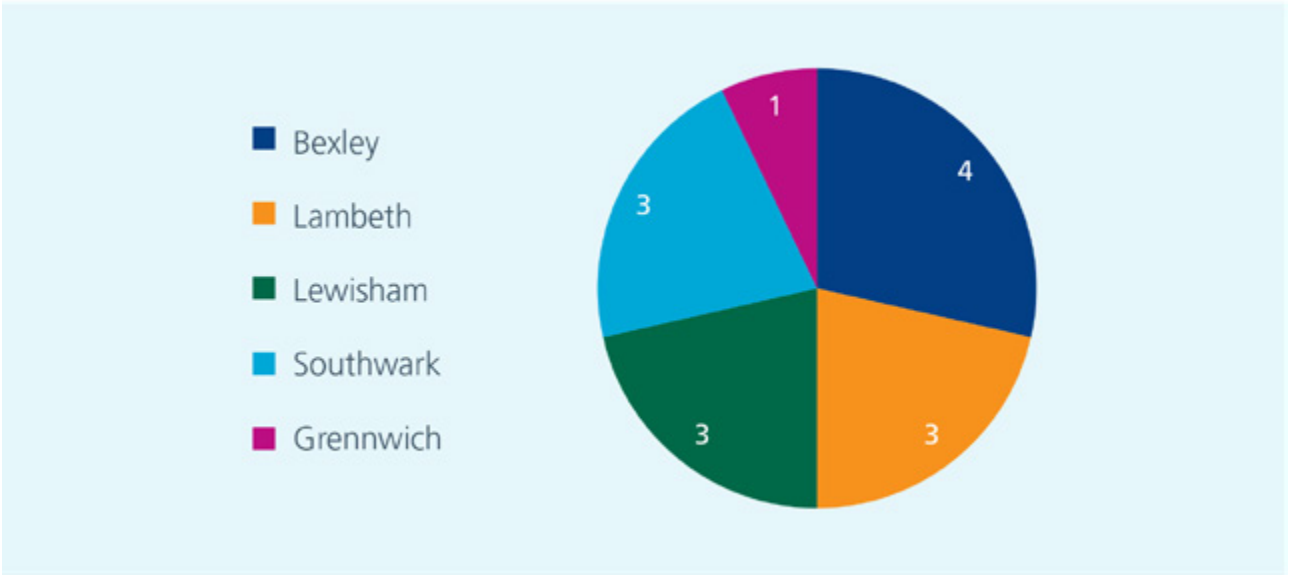


Figure 3.9 Number of focused reviews with accommodation care concerns

Concerns about the quality of care received included:

- Care providers not reporting safeguarding concerns to social services.
- A lack of recognition that self-neglect should be raised as a safeguarding.
- Care providers not updating social services regarding changes in need of the person they were supporting or difficulties they were experiencing in supporting the person with the tasks they had been commissioned to do. For example, a care provider commissioned to support a person with managing their correspondence and attend their health appointments, however the person did not attend their GP Annual Health Check for 8 years despite the GP inviting them regularly. The care provider did not flag up difficulties with supporting the person to attend health appointments.
- Medication administration errors within a residential home related to reliance on agency staffing, not having an adequate number of staff on duty and inadequately trained staff.
- People being cared for in an inappropriate environment with unskilled staff due to difficulties in finding appropriate placements.
- Symptoms of pain not acted on due to being viewed as behavioural problems.
- Carers not following eating and drinking guidelines.
- Family carers declining medical intervention and support on behalf of the person they were supporting without the Mental Capacity Act being followed.

Areas of good practice

From the 54 LeDeR reviews completed in 2023-2024 Reviewers identified the following examples of good practice.

- The input of Learning Disability Liaison Nurses to address barriers to care in hospitals.
- End of life planning being carried out and plans being followed.
- People being supported to attend medical appointments by care staff who know them well.
- Collaborative working across professions and organisations.
- Involvement of the person and their family in care and decision making.
- The use of reasonable adjustments, for example home visits, longer appointments, easy read information, telephone appointment making.
- Care providers ensuring that the person was supported to health appointments by staff who knew them well to make sure that their phobia of needles did not prevent them from receiving vaccinations, blood tests and dental treatments.
- Psychiatry input during hospital admission. Person was visited frequently on the general hospital ward by community mental health professionals, including psychiatrist.
- Effective collaborative working between GP, Community Learning Disability and Palliative Care Teams with ongoing consideration of capacity and decisions made in the client's best interests.
- Excellent multidisciplinary teamwork between all professionals, family, and care providers.

Areas requiring change

From the 54 LeDeR reviews completed in 2023-2024 Reviewers identified the following examples of key areas requiring change. Whilst some of these are similar to our previous report, new areas of change have also been identified, with our data set continually growing. Learning into action on page 44 identifies just some of the work that is or has taken place across South East London to improve those areas requiring change identified in the last year. Actions and improvements from this reporting year will be fed back in our 2024-2025 report.

- Mental Capacity Act processes not being followed. Particularly a lack of decision specific capacity assessments and best interest decision making processes. Also, Independent Mental Capacity Advocates (IMCAs) were not always referred to when needed.
- Lack of clarity over the legal powers of relatives, for example deputyship and Lasting Power of Attorney, resulting in decisions about care and treatment being made on a person's behalf without the correct legal process being followed.
- At the time of writing this report both the Mental Capacity Act and legal powers of relatives have been highlighted to the South East London Learning From Deaths Group, and will be addressed as part of Oliver McGowan training, as well as in learning and communications events with NHS providers and local authorities.
- Lack of co-ordination of support and information sharing across services, particularly in relation to safeguarding concerns.
- Negative experiences of hospital admissions, for example pain not being recognised.
- Lack of follow up into missed medical appointments when the person required the support of others, paid or informal carers, to access these appointments.
- Lack of timely response to the safeguarding alert raised.
- Lack of investigation into long-standing non-compliance of medication and lack of attendance to health appointments which increased risks to physical health.
- Health action plan appeared cursory and had minimal information. A comprehensive health action plan may have helped with spotting symptoms and signs of poor health at an early stage.
- GP practice focused on treating presenting symptoms rather than a consideration or investigation of wider causes.
- Disparities faced by those from an ethnic minority community in particular under reporting to LeDeR and the correct use of DNACPR.
- Management of Long-term health conditions in particular frailty and continence.

Learning into action

Working closely with key partners/service providers and our LeDeR Local Leads, below are just some of the projects/initiatives taking place across South East London that are making a positive impact to those with a learning disability and autistic people.

SEL Learning Disability and Autism Programme

For 2023-2024, the SEL LDA programme had five priority actions:

1. Developing a strategic response to Autism
2. Developing a South East London care and support offer for people with a learning disability and autistic people
3. Developing the learning disability and autism workforce
4. Reducing long term inpatient care for people with a learning disability and autistic people
5. Improving quality of life and care for people with a learning disability and autistic people

Achievements include:

- Established SEL Core Offer for CYP Autism Assessment Pathway.
- Produced SEL Autism Strategic Framework.
- Monitored and evaluated clearance of waiting lists and times for autism diagnosis with providers.
- Established the LDA Pathway Fund Panel to support the discharge of inpatients and develop community accommodation, care, and support.
- Contribution to development of FIND - Forensic Intellectual and Neurodevelopmental Disabilities service to meet needs in the community.
- Implemented Task and Finish Group to work on the implementation of Oliver McGowan Training across SEL.
- Continued to build on developing and expanding the SELECT Key Working Service to meet the need of children and young people across SEL, who are on Dynamic Support Registers.
- Delivered Care Education Treatment Reviews (CETRs) and Dynamic Support Registers (DSR) sessions across ICS services and agencies.
- The rate of admission for adults has halved since 2019 from an average of eight (8) admissions per month to four (4). This has led to a significant reduction in non-secure and secure inpatients and the achievement of target.
- Supported local areas to develop and improve Dynamic Support Registers (DSRs) for all ages and implement operational procedures for the new DSR guidance.
- Supported implementation of a Community of Practice - SEL Core Offer for Community Health services for SEND (Special Educational Needs and Disability).

Learning Disability and Autism Specialist Prescribing Team

As premature deaths and unnecessary hospital admissions are prevalent within the Learning Disability and Autism (LDA) communities, adversely affecting both patients and their caregivers. To ensure that high-quality, relevant knowledge is disseminated among health and social care professionals in South East London, the specialist prescribing team collaborates with the broader LeDeR team to identify and address potential health gaps that could be mitigated to prevent future premature deaths. The team provide expert insights into the primary care system, enhances understanding of medication use in primary and community settings, and advocates for holistic care. This partnership leverages LeDeR case studies to implement best practices, thereby benefiting all clinicians across the boroughs in South East London. Notably, protected learning time (PLT) events are highly regarded by general practitioners, nurses, and other allied health professionals, best practices are shared by the prescribing team at these events to ensure high standards of clinical care and outcomes are consistently provided to people with a learning disability and autistic patients.

The team worked on increasing uptake and quality of Annual Health Checks by providing a large number of both local and national specialised training, webinars, and workshops to healthcare professionals, regarding the specific needs of individuals with learning disabilities and autism. This includes understanding effective communication strategies, and the importance of reasonable adjustments.

Raising awareness about learning disabilities and autism among clinicians is vital for providing inclusive, equitable, and effective healthcare. It helps to increase confidence and competency and address the unique needs of these patients, reduces health disparities, and promotes better health outcomes.

Providing good quality annual health checks for individuals with learning disabilities and autism provides numerous benefits, early detection and management of health conditions, improved quality of life, better mental health outcomes including STOMP (stopping over medication for people with a learning disability and/or autism) to reduce unnecessary medications, increased life expectancy, enhanced patient and caregiver satisfaction, cost savings for healthcare systems and addressing health inequalities.

The team has seized the opportunities to highlight the importance of proactive care like screening and vaccinations. Additionally, the team have participated in engagement events to educate individuals with learning disabilities and autism and their caregivers, empowering them to take greater control of their health.

Working closely with South East London practices, the team made great efforts on improving the learning disability diagnostic and prevalence. Having the right patient on the learning disability register on GP systems is vital for ensuring that individuals with learning disabilities receive appropriate and personalised healthcare through high quality annual health checks and by ensuring reasonable adjustments are made. This improves health outcomes, facilitates effective communication and coordination, increases access to specialised services, and ensures better data collection and policy development. Overall, it plays a crucial role in addressing health inequalities and promoting the well-being of individuals with learning disabilities.

Bexley, Bromley, and Greenwich: Dietetics Scoping Project

A 12-month scoping project across the 3 Oxleas boroughs (Bexley, Bromley, and Greenwich) has been successfully completed to scope the dietetic needs of the local learning disability population and make links with local services including Public Health to plan for an equitable and accessible pathway for people with learning disabilities. The report with recommendations has been published and as a result a substantive specialist Adult Learning Disability Dietitian post has been agreed.

Bexley, Bromley, and Greenwich: Respiratory Assessment Tool

A respiratory assessment tool has been chosen and is in use by clinicians assessing people with respiratory conditions/presentations. A new pathway is now in place to ensure that clients identified as being 'at risk' are appropriately referred on to specialist respiratory services. Training is being shared across and outside adults with learning disabilities.

Bromley: Recognition Award 2024

The One Bromley Learning Disability Taskforce Team were awarded The One Bromley Recognition Award for their proactive care of people with learning disabilities, increasing the number of people having annual health checks and improving the quality of the checks.

Bromley: Learning Disability Co-Ordinator

Successful implementation of a Learning Disability Coordinator resulting in the Primary Care Network now looking to appoint 8 individual Learning Disability Champions for each Primary Care Network.

Bromley: Epilepsy Risk Assessment Management Plan

Bromley Learning Disability Epilepsy Service: All adult learning disability nurses have been trained to use the RAMP (Risk Assessment Management Plan) as part of the Learning Disability Epilepsy Pathway and audit results have evidenced high quality effective assessments and care plans. Furthermore, annual specialist Learning Disability Epilepsy masterclasses have been established and developed to many medical and nursing staff across the country.

Bexley: Constipation Training

A training package/resource has been developed looking at existing resources and guidance with a view to producing a training/information resource for staff and service users, delivery will commence at the end of the summer 2024.

Lambeth, Lewisham, and Southwark: Living and Dying Well Group

The Lambeth, Lewisham, and Southwark community team for adults with learning disabilities together with South London and Maudsley and St Christopher's hospice, have set up a Living and Dying Well Group for people to come together to think and talk about Life and Death. The group is incorporating the 'No Barriers Here' arts-based approach to Advance Care Planning.

Lewisham: People's Parliament

Lewisham Speaking Up run regular People's Parliaments on topics of importance to people with a learning disability in the Lewisham borough. Topics have included housing, employment, mental health, race equality and self-advocacy and in July 2023, health. Some of the issues covered at the health parliament included: Why are people with learning disability dying too young? cancer awareness and screening and how to eat healthy in a cost-of-living crisis. Parliament reports are available through the Lewisham Speaking Up website: www.lsup.org.uk Lewisham Speaking Up is also part of the 'We Can't Wait' campaign with My Life My Choice. This campaign is focused on getting people with learning disabilities prioritised on NHS waiting lists to stop people from dying before their time.

Looking Forward

From the findings and learning identified within the 54 reviews completed between 1st April 2023 to 31st March 2024, the LeDeR team will focus on the following areas of work.

- Continue to raise awareness of the LeDeR Programme within all health and social care providers across SEL, with a focus on creating more awareness of the inclusion of autism to ensure all deaths of individuals with a learning disability or autistic people are notified to the LeDeR Programme and their death reviewed.
- Continue to work with our providers and stakeholders to promote and encourage more notifications for people from ethnic minority backgrounds, to help us better understand the specific health inequalities and barriers these groups face.
- Continue to work towards embedding learning from LeDeR reviews into transformation and service improvement projects.
- Raise key themes and issues identified in this report at the South East London ICS Strategic Group meeting and other key governance meetings in the 6 boroughs in South East London. Ensure actions are identified to address these, improve care delivery and reduce preventable mortality of people with learning disability and autistic people in South East London
- Continue to work with Local Leads from the 6 boroughs and partners across SEL to deliver LeDeR engagement activities, including in-person activities and virtual webinars.
- Continue to identify the recurring themes from reviews undertaken of those from an ethnic minority community and those from the wider autistic community, to identify priority areas for improvement.
- Develop a SEL ICS Task and Finish group to review LeDeR Governance Groups – Focused Review Panel and LeDeR Strategic Group and ensure the aims and objectives are still being met and the appropriate people are in attendance to implement change.
- Continue to work closely with the South East London Annual Health Check Steering Group to promote the uptake of annual health checks to ensure every person with a learning disability aged 14 years and over are invited and supported to attend annual health checks.
- Area of focus – a deeper dive into oral health and the risks associated with community acquired pneumonia and the use of DNACPR for those from an ethnic minority community.
- Review and streamline the LeDeR process to ensure we have better pathways for supporting action and change.
- To share our findings in relation to long term health conditions with our South East London ICS Strategic Group meeting and other key governance meetings to help us systematically identify how we can link in with specific teams such as frailty and continence to ensure people with a learning disability and autistic people are getting the right support to manage their long-term conditions.
- Undertake further work to correlate and identify the recurring themes and pathways that are detrimentally impacting on the responsiveness of ICS services.

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Appendix 1

Careful forward planning is important to ensure appointments are effectively utilised. Appropriate reasonable adjustments should be made such as easy read documents, keeping language simple and providing longer appointments if possible. The potential for support from their carer, family member or the community learning disability nursing service should be considered.

History and review of systems

- Past respiratory history including episodes of previous pneumonia, requirement for antibiotics, past hospital admissions, prescribed respiratory physiotherapy and use of assisted ventilation
- Medication review including anti-epileptic drugs, psychotropic medication and regular antibiotics
- Review of long-term conditions such as epilepsy, diabetes or renal disease
- Specific questions regarding eating, drinking and swallowing to include choking, coughing when eating, or food 'getting stuck'
- Specific review of symptoms which may identify risk factors for aspiration such as drooling. symptoms of gastro-oesophageal reflux (heartburn, waterbrash, vomiting, rumination etc) or uncontrolled seizures
- History suggestive of sleep disorder breathing such as excessive daytime sleepiness, habitual loud snoring, witnessed apnoea during sleep, nocturia, morning headache or nausea
- History suggestive of impaired airway clearance including history of difficulty clearing secretions and crackles, bubbling sounds or coarse wheezing at the mouth during coughing or deep breathing
- Dental history (including oral hygiene regimen and history of previous dental care)
- Immunisation history (specifically influenza and pneumococcal vaccines)
- Physical activity (any recent changes)
- Smoking history including exposure to smoke from family members and carers

Examination

Examination should consider:

- Weight, height and BMI calculation. Consider the use of wheelchair scales.
- Baseline observations such as pulse rate, temperature, oxygen saturations and respiratory rate to facilitate identification of physiological change in acute illness
- General assessment of posture (including scoliosis) and muscle tone
- Assessment for cough strength and character
- Assessment for excessive oral secretions (drooling, gurgling)
- Assessment of oral health including teeth (decay, acid erosion), gums, tongue and buccal mucosa
- Presence of tracheotomy, enteral feeding tubes
- Signs of sputum retention including crackles or bubbling sounds at the mouth during coughing or deep breathing, palpable secretions, audible crackles or wheeze on chest auscultation (which may clear after coughing

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