NHS South West London
Integrated Care Board

“Learning from Lives and Deaths” People with a learning disability and autistic people. Mortality Review (LeDeR), Annual Report 2023/2024

Incorporating the Boroughs of: Croydon, Kingston, Merton, Richmond, Sutton, and Wandsworth

Authors: NHS South West London ICB LeDeR Team

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1. Introduction

This report is the 4th Learning Disability Mortality Review (LeDeR) annual report for Southwest London (Integrated Care Board (ICB) and previously the Clinical Commissioning Group). The ICB, all partner organisations, and commissioned services are committed to working together and to learn from each other to make a positive difference and improve the health of people with a learning disability and autistic people.

The purpose of the report is to share our findings from LeDeR reviews. This report gives an overview of the reported numbers of deaths, demographics and cause of death within Southwest London, for people with a Learning Disability and/or Autism, and covers the 6 boroughs of Croydon, Kingston, Merton, Richmond, Sutton, and Wandsworth.

In SW London there are approximately 6,830 people with a learning disability aged 14+ who are on a GP Learning Disability Register and 16,178 people in SW London who are coded as being autistic.

2. What is LeDeR and why is it important?

The Learning Disabilities Mortality Review Programme (LeDeR) was established in 2016 to contribute to improvements in the quality of health and social care for people with a learning disability in England. LeDeR was established to gain a greater understanding of why people with a learning disability and autistic people die earlier on average than the rest of the general population, and do not always receive the same quality of care.

All deaths of people with a learning disability over the age of 4 years are subject to a review and in January 2022 NHSE introduced LeDeR reviews for autistic people who do not have a learning disability. The LeDeR programme is now referred to as “Learning From lives and deaths. People with a learning disability and autistic people”.

LeDeR is not an investigation process into the deaths of people, rather a service improvement programme with its purpose to review the care and treatment of people prior to and during the last phase of life. It acknowledges and promotes good practice, as well as highlighting areas where there have been issues and where care could have been better, to give recommendations on how these issues can be improved

3. Acknowledgement of the input and support from families and participants of the reviews

We must not forget each notification is a notification of a loss. We would like to acknowledge family members, friends, health and social care staff and many others who have contributed to a LeDeR review by sharing their experience of the life and death of a loved one or someone in their care.

These important people are key to understanding who the person was. This personal information is obtained through a pen portrait, a detailed description of the person, including who and what was important to them, their likes, dislikes and routines. We want to ensure the voices of people with a learning disability and their families and carers are at the heart of our work.

4. Executive summary

When summarising and reflecting on SW London LeDeR Programme for 2023/24 we have used Rolfe's (2001) reflective model which will consider the programme through these 3 questions. **What , So What, Now What?**

What - have we done as a LeDeR Team? We have collated demographic information on 88 notifications of deaths about people in the boroughs of SW London, via the National LeDeR Platform for 2023/24. We have been able to analyse 66 completed reviews for themes and learning. We have done this by designing a new data base that allows easy extraction of data.

To ensure that we are adhering to the National LeDeR Governance Process and Policy we have a new Quality Assurance Panel, that quality checks completed reviews before they are presented at local steering groups.

We have met with local community, acute and social care providers to improve relationships and information sharing to allow for timely and informative reviews.

So What? do we know from SW London LeDeR Reviews. **The average age of death of someone with a learning disability and/or autism was 61 years of age**, and 45% of these people were over the age of 65. **The majority of these deaths were women who accounted for 55% and men 45%** this is in contrast to National LeDeR figures, where it was reported more men, with a learning disability and/or autism are dying than women.

The LeDeR Team reviewed 3 people who had a diagnosis of autism, this is an increase from last year when none were reported. We do know that this figure should be higher and increasing knowledge on reporting is a priority for the team in this coming year.

The leading cause of death was Aspiration Pneumonia, this is the same as last year and is now a priority for the SW London LeDeR team, National LeDeR data shows circulatory disease and Ischemic Heart Disease being the main cause of death. Most people whose deaths were

notified to the LeDeR platform have died in hospital and this was recorded as 57% of all notifications. This is a lower figure than was reported on last year in SW London when 68% of people were reported to have died in a hospital.

Within the 66 completed reviews, we know that **80% of people had an Annual Health Check** which is above the National average of 72% and the target set in The NHS Long Term Plan of 75%. Of these Annual Health Checks 70% led to a Health Action Plan being put in place. There was evidence of early recognition and planning around End-of- life care **with 62% of people being on an end-of-life care pathway** and 68% of people had a Do Not Attempt Cardiopulmonary Resuscitation decision. **Reviews showed that 76% of people who needed a Mental Capacity Act assessment had one undertaken and 86% of these were completed correctly.**

Quality and effectiveness of care is reported on for people who have a focused review, where a score of 1 represents poor care and a score of 6 represents excellent care. **The average grade for quality and effectiveness of care was 4 , which according to the LeDer policy means care was satisfactory**, but did not significantly impact on the persons wellbeing. There were however 13% of people whose care had been scored as 2, which means care fell short of expected good practice. The reasons have been highlighted under themes learnt from reviews which included specific training, the need for improved communication and joined up service delivery.

We found many examples of good care by providers in SW London. It was reported that Individuals and Teams went over and above to ensure excellent care for people with a learning disability, highlighting flexibility and collaborative working. There was evidence of people often being at the centre of their own care with professionals enabling autonomy and respect for individuals' choices.

Now What? As a new permanent SW London LeDeR Team we have determined 3 priorities based on the findings from this report to help address some of the inequalities faced by people, and those who care for them, with a learning disability and/or autism.

1. **Aspiration Pneumonia** is the leading cause of death for people with a learning disability/ and or Autism in SW London- accounting for 26% of deaths in 2023/24. A further in-depth analysis of deaths caused by Aspiration Pneumonia will be undertaken plus a scoping exercise to understand National and Local initiatives and support a system wide approach to address this area of need.

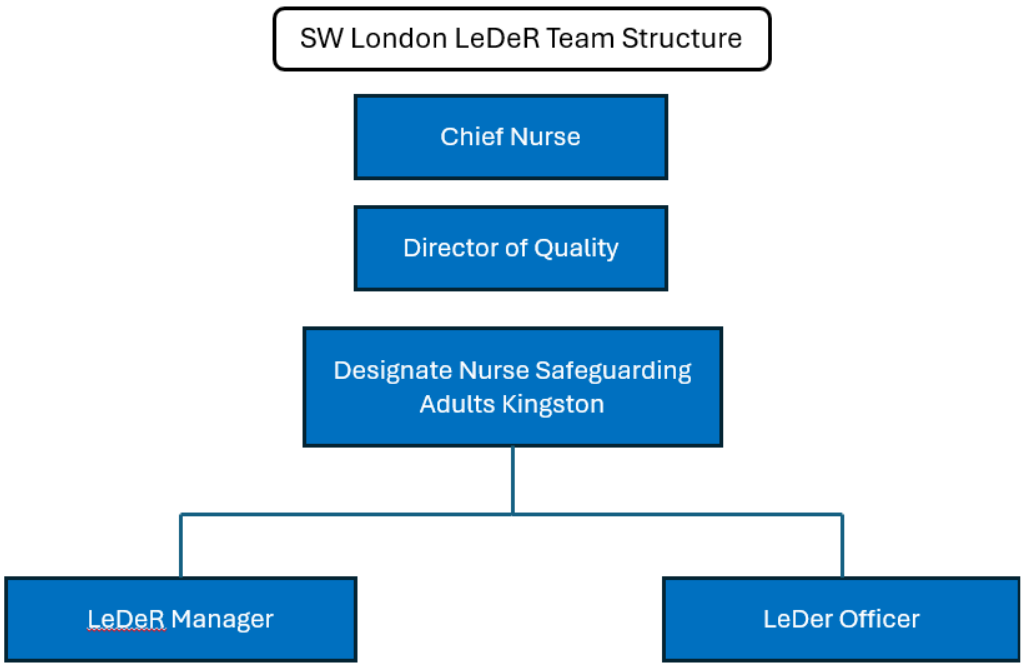
2. **Deaths outside of hospital** accounted for 35 out of the 66 deaths last year for people with most people dying in hospital. Whilst it may have been appropriate for these deaths to occur in hospital there will be a piece of work undertaken to understand if people were dying in their preferred place

3. **Increase notifications of deaths of autistic people for SW London**. There were 3 notifications of deaths for people who had a diagnosis of autism. It is believed that awareness of reporting deaths, for this group, is low. A SW London awareness campaign is to be undertaken, with the aim of improving reporting and allowing greater understanding of the issues that affect people with autism.

5. The SW London ICB LeDeR Team and partners in south west London

The LeDeR policy recommends that each ICS sets up a team of dedicated reviewers and has a Local Area Contact (LAC) to have sole focus on conducting thorough reviews, ensuring all are completed in a timely manner. Learning and good practice identified within reviews needs to be shared across the whole ICB as well as the national LeDeR team.

SW London ICB since April 2024 have a dedicated full-time LeDeR team to undertake reviews. The structure below shows overall governance of the SW London LeDeR Programme. Overall responsibility at a strategic level, remains with the Chief Nursing Officer and Director for Quality, who assigns the day-to-day operational management to the Local Area Contact. Local reviews and provider engagement is undertaken by the LeDeR Manager and Officer.



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Local steering groups

There are 3 local LeDeR steering groups within SW London, Kingston & Richmond, Croydon and Merton, Sutton and Wandsworth. The main purpose of the steering group is to ensure any delays of progressing a review are addressed, to consider local recommendations from local reviews and turn plans of action into learning.

These steering groups meet quarterly to consider local reviews and recommendations and support work streams to turn actions into learning. Representation includes people with a learning disability, family and carers, health and social care representatives and representatives from community and acute trusts, voluntary organisations and GP's.

Governance

Quality Assurance Panel

A New Quality Assurance Panel has recently been established with a multi professional membership from health and social care agencies across SW London. Its purpose is to quality check completed focused reviews and ensure accuracy of clinical information being recorded in the reviews before they are presented at local steering groups.

Safeguarding adults boards – Quarterly data

In the Southwest London area, the LeDeR programme is taken to be part of the overall safeguarding agenda. Each safeguarding adult's board usually receives a quarterly update from the LAC on the progress of reviews and updates on any work streams as part of the learning into action. The programme is always vigilant to ensure that if safeguarding concerns are identified that the appropriate type of review is undertaken. This could include the review being undertaken as a Safeguarding Adult Review rather than a LeDeR review.

Learning Disability Partnership Board – Kingston only

Some boroughs also have a learning disability partnership board with a broad membership that includes people with a learning disability, families and carers, local councillors, health and social care representation, employment, and housing. The partnership board includes a specific health subgroup which focuses on the health needs and services of the local population. The LeDeR programme is a main focus for these groups and progress on work is monitored here too.

ICB/ICS system wide learning and reporting

Learning, issues and information on positive practice that have been highlighted in the LeDeR reviews are reported on quarterly to local place committees and high level ICB governance boards and committees. as well as the board receiving the annual Learning from Lives and Deaths report for approval and publishing.

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6. Local and national LeDer process

NHS England have set up a web-based platform for reporting deaths. This platform allows anyone; family friends, members of the public or people from health and social care organisations to report on the death of a person with a learning disability and/or a person with autism.

Visit the online platform for reporting and for information on the "Learning from Lives and Deaths"

This platform is accessible to SW London LeDeR Team who allocate and monitor reviews. SW London LeDeR team have set up a database to capture review data and learning. The reviewer will carry out an initial review using the new web platform to guide them through the process - there are two types of review for the LeDeR programme, "Initial" and "Focused".

Initial review	focused review
An initial review will include: - a guided conversation with a family member or someone close to the person who died, this might also be someone they lived with or carer who they were particularly close to - the detailed conversation with the GP or a review of the GP records which will be accessed via a smart card where possible giving direct access to the GP system - a conversation with at least one other person involved in the care of the individual who died - Might be for example the person who carried out the mortality review in the hospital (if they died in an acute trust) or simply another family member who wants to speak to the reviewer about the care their loved one received	Situations where a focused review will be carried out are: - if the individual is from a Black, Asian or minority ethnic background, a focusd review will automatically be completed due to significant under reporting and increased health inequalities in these communities (This may include, for example, and not be limited to, Romany gypsy, Irish traveller or Jewish communities) - If in the professional judgement of the reviewer that there is significant learning likely for the ICS from carrying out a LeDeR review - if there are concerns about the quality of care provided to the person by one or more providers or there is evidence of lack of integrated or coordinated care - in the years 2021 to 2023 all deaths of adults who have a diagnosis of autism but who do not have a learning disability will have a focused review

*Learning from lives and deaths – people with a learning disability and autictic people (LeDeR policy (2021)

The SW London LeDeR Team also links, via monthly meetings, to the regional London LeDeR

Network where National updates and learning is shared. A “community of practice” for South London is currently being formed to support local LeDeR reviewers.

7. Completed reviews

In the year 2023/24 reviews were being undertaken by a reviewer team employed by the ICB on a bank staff basis, the team was made up of 4 experienced reviewers, who had worked on the LeDeR program for a number of years. After a re structure across SW London ICB and approval of 2 full time permanent staff, LeDeR manager and reviewer posts, the ICB were able to advertise and appoint to these posts. The LeDeR Manager started in post mid-April and a new LeDeR Officer started in post at the end of June 2024. This new team has undertaken training and a period of induction to SW London ICB and partners.

There were 88 deaths of people with a learning disability or autism reported to SW London via the LeDeR Platform, for the financial year 2023/24. There were 23 focused reviews and 65 initial reviews. 66 reported reviews were completed and presented at local Steering groups where the learning from reviews was shared. This is a difference to the previous year when there were 86 notifications. As of 1st April 2024, there were 51 reviews which needed to be completed, there has been some delay in completion and starting of reviews with the new team structure.

The report in respect of its findings from 23/24 has been split into 2 sections. Part 1 will focus upon the Deaths in 23/24 from the notifications received upon the LeDeR platform. This will examine the demographics of the 88-sample group. Part 2 has focused on those reviews in 23/24 that were completed the 66 by LeDeR Reviewers.

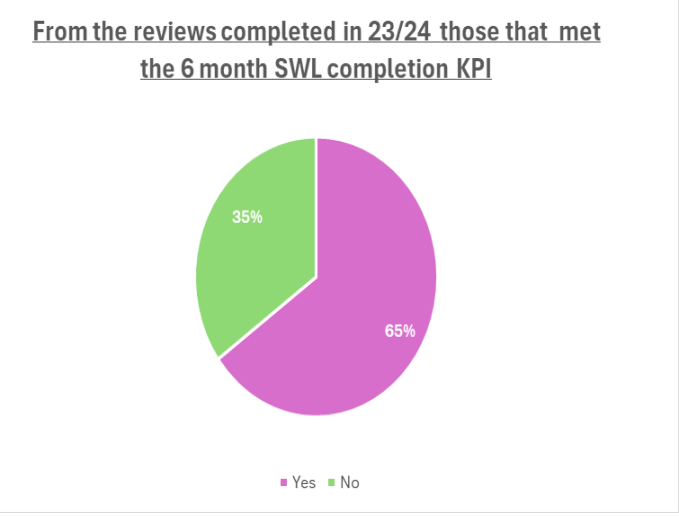
Reviews completed in 23/24	Child death overview process	Initial	Focused	Total
Total reviews completed from 1st April 2023 to 31st March 2024	3	40	23	66

Deaths in 23/24	Initial	Focused	Total
Total notifications 1st April 2023 to 31st March 2024 (Those that died in 23/24 only)	65	23	**88**
As of the 1st April 2024 reviews outstanding (Those that died in 23/24 only)	39	12	**51**

Key Performance Indicators (KPI)

NHS England target for reviews is for reviews from notification to completion to take 6 months. In SW London it has taken on average 187 days, 6 months approximately. The pie chart shows the

% of the 66 reviews which met the 6-month KPI timescale versus those that went beyond the prescribed time frame. 43 reviews were performed within the 6-month KPI whereby 23 took longer to complete.

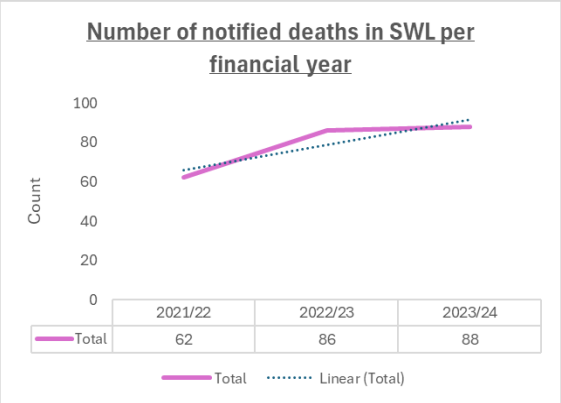


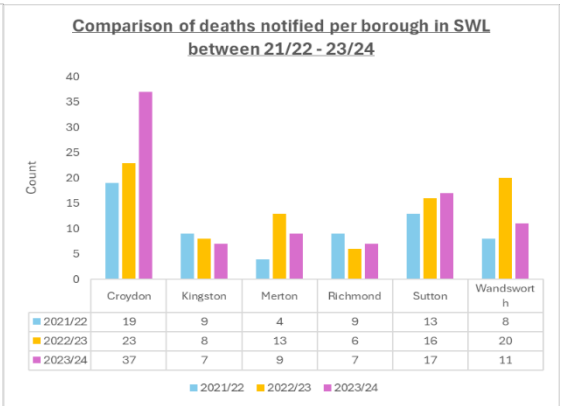
LeDeR review data is further classified and broken down by SW London Boroughs, with Croydon having the largest number of notified deaths. There were 3 notifications for people with a diagnosis of autism compared with last year where there were none notified or reported on. We still believe this number should be higher and is a priority for the team to look at improving reporting of deaths for people with an autism diagnosis in 2024/2025.

Locality	Autism	LD	LD & Autism	Grand Total	%
Croydon	1	30	6	37	42%
Kingston	1	5	1	7	8%
Merton	0	5	4	9	10%
Richmond	0	6	1	7	8%
Sutton	0	12	5	17	19%
Wandsworth	1	9	1	11	13%
Grand total	3	67	18	88	n/a
%	3%	76%	20%	n/a	n/a

Number of deaths in SWL 2023 to 2024

These charts shows the steady increase in the number of notified deaths since 2021 through to 2024 across the different boroughs in SW London.





Child Death Overview Process (CDOP)

During 2023/24 there were 3 cases notified to the LeDeR platform, which related to the death of a child with learning disabilities. All child deaths are reviewed as part of the statutory Child Death Overview Process (CDOP) and therefore separate LeDeR reviews are not undertaken and counted in the data.

8. About the people who died

Age

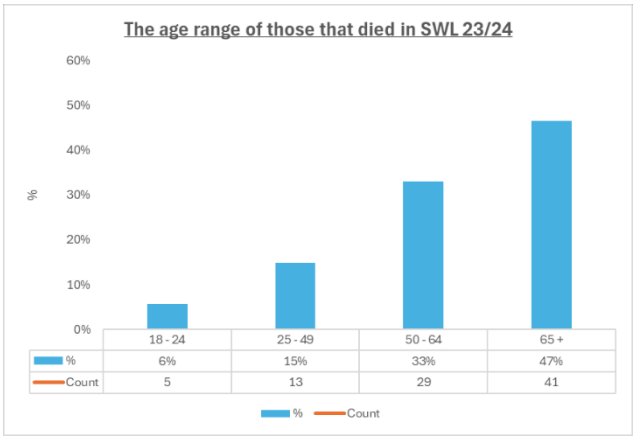
This chart shows the average age of death of those that died as 61 years of age, and the comparison of age of deaths since 2018/19. National LeDeR data shows the average age of death is 62.9. By contrast, the average age of death among the general population is 81 years and ten months so we can conclude that people with a learning disability in SW London have a shorter life expectancy than the general population.

2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	National average age of LeDeR deaths
58.9	58.4	57	54.8	62	**61**	**62.9**

The average (mean) age of deaths in SWL

This Chart shows the age range of deaths for people with a learning disability and or autism in

SW London. The majority of people , 47 %, are dying over the age of 65, suggesting that in 2022/23 people with a learning disability in SW London are living longer.

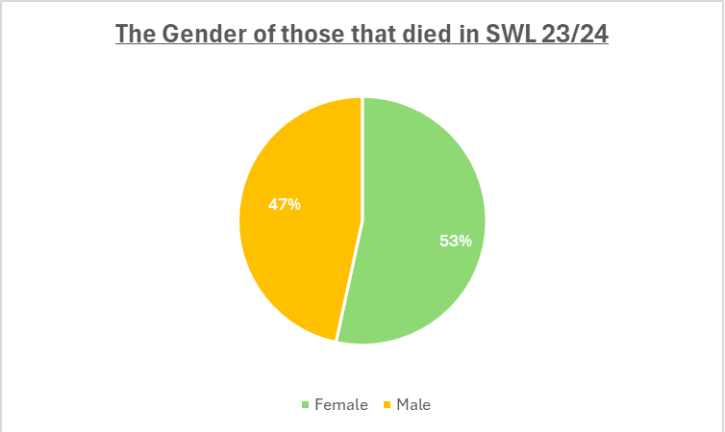


Gender

The gender of people who died, in SW London LeDeR reviews shows that 53 % of deaths were women and 48% were men . This is in contrast to the most recent National Annual LeDeR report which states that 55% of reported deaths were men. This higher proportion of women dying is similar to last year when 55% of deaths were female and 45% male. There is no apparent reason for this disparity we will continue to monitor these figures through 2024/25. There were no notifications of people who identified themselves as non-binary.

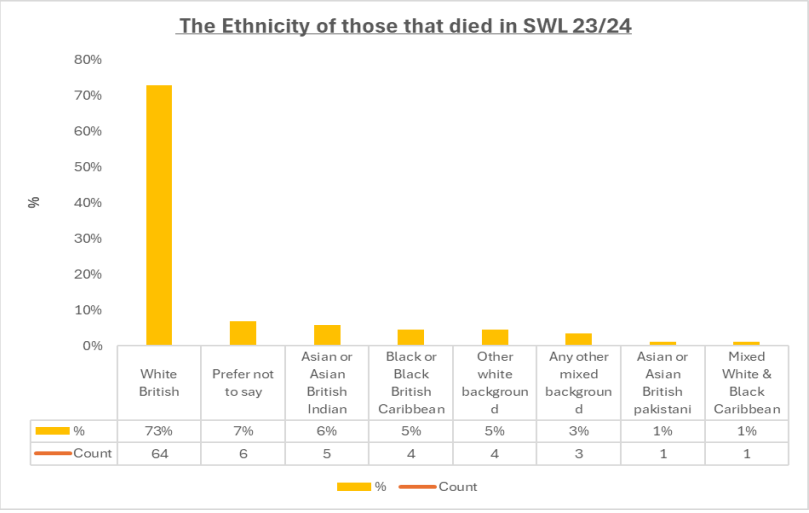
The Learning from lives and deaths – People with a learning disability and autistic people Annual Report 2022 Learning from Lives and Deaths - people with a learning disability and autistic people (LeDeR) | King's College London (kcl.ac.uk)covered deaths notified to the programme during 2022, the reported genders were:

1. 55% identified as male.
2. 45% identified as female.



Ethnicity

The graph below shows a break down on the ethnicity of people who have died and reported to the LeDeR platform for SW London. The highest number of notifications reported were 73% from a White British background this figure is lower than 2022/23 , which was 79 %. The reporting of deaths of people from black and all ethnic groups combined is much lower than deaths reported on for white people. Considering the diversity within SW London it is an area that needs to be monitored.



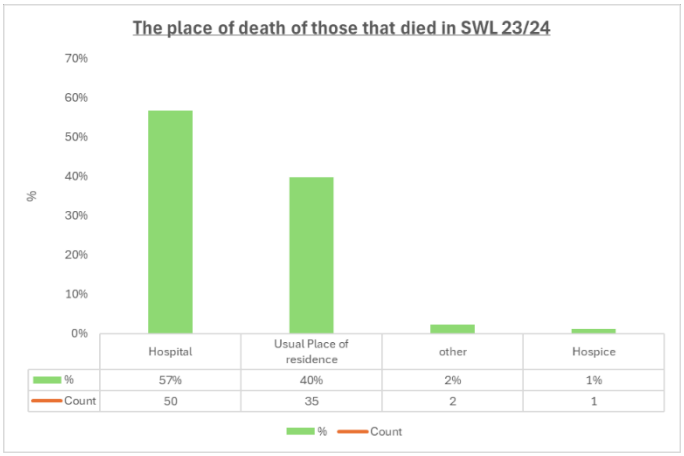
In LeDeR national reporting People with learning disabilities and/or autism experience health inequalities and those in ethnic minority communities are further disadvantaged and under-represented as users of learning disability and autism health services. This highlights common issues related to intersectionality. In SW Lonodn there was no noted difference in the quality and effectiveness of care for focused reviews across all ethnicities in SW London

A question which was posed by stakeholders has been the link to ethnicity and age of death. Notifications of deaths of people from Black and ethnic groups combined from the 88 notifications has been low considering the cultural diversity in SW London. When the data was analysed to consider if there was a higher percentage of people from Black and ethnic groups combined dying at a younger age no significant data was found.

Place of death

National LeDeR data shows us that 57% of deaths occurred in hospital. This is the same figure in SW London with 40% of people dying in their usual place of residence, and 5% dying in hospices. Less people are dying in hospital compared to the 2022/23 report, where 68% of people died in hospital in SW London. Although these deaths in hospital may have been

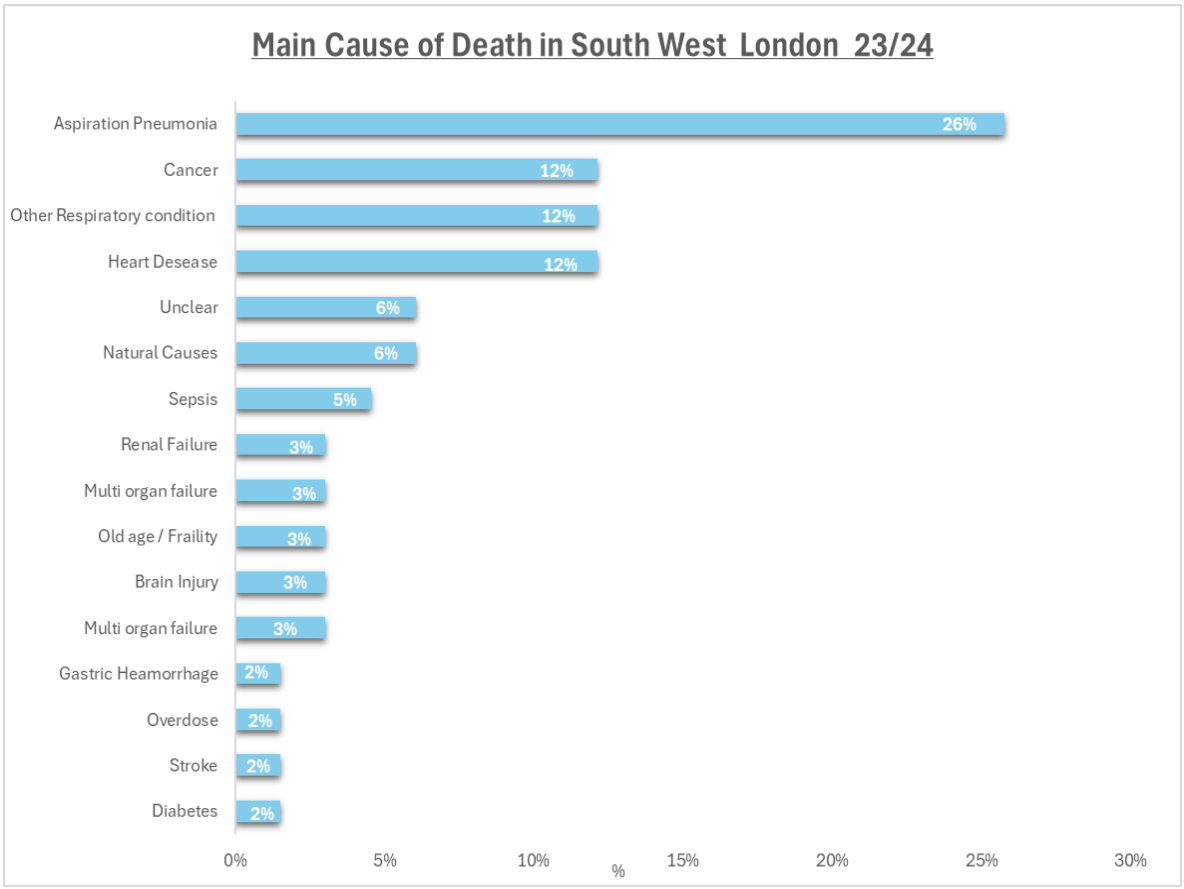
appropriate, we have made this a team priority, to explore if people are indeed dying in their preferred place of death.

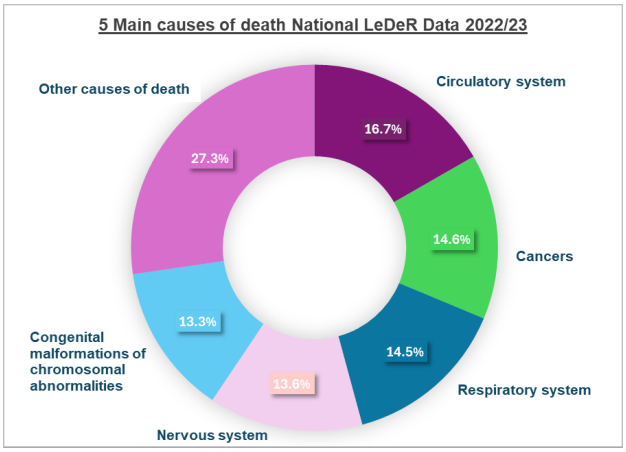


9. Cause of death

The most common cause of death in SW London for 26 % (n=17) of people with a learning disability and autism is Aspiration Pneumonia, as recorded in part 1a of the death certificate (properly, the Medical Certificate of Cause of Death, MCCD). This has been a leading cause of death for previous years in SW London. This compares national LeDeR figures where 17% of deaths were related to respiratory disease and 8.44% of these due to Aspiration Pneumonia. Due to this disparity, we will be conducting an in-depth analysis of the deaths caused by aspiration pneumonia.

Cancer, other respiratory conditions and heart disease are the second most common cause of death in SW London. National LeDeR Figures show circulatory disease is the main cause of death and Ischemic Heart Disease being the most common condition within these deaths.





10. Annual Health Checks (AHC)

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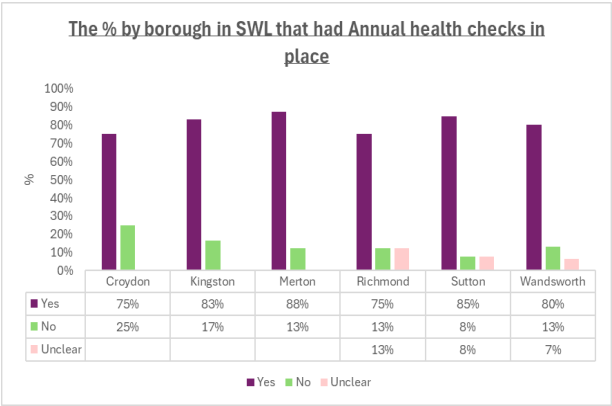
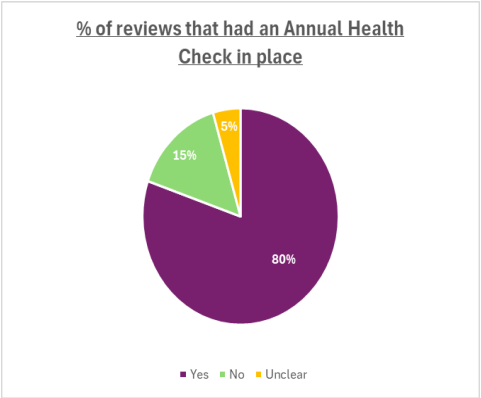
Annual Health Checks (AHC) are available to anyone over the age of fourteen who is identified on their GP's learning disability register. Evidence suggests that providing health checks to people with learning disabilities in primary care is effective in identifying previously unrecognised health needs, including those associated with life-threatening illnesses. The NHS Long Term Plan set an ambition that by 2023/24, at least 75% of people aged 14 + with a learning disability will have received an AHC

National LeDeR figures show that 72 % of people had an Annual Health Check. SW London achieved above the National average, as 80% of people had an AHC. This figure however is lower than last year within SW London when 84% of people with a learning disability had an AHC. Every AHC should be supported by a Health Action Plan, which sets out the health goals the GP and their patient agree, 70% of people had a health action plan (n=43/61)

One aspect of a Health Action Plan is to ensure cancer screening is undertaken, for 65% of reviews it was unclear if that person had been involved in any NHS cancer screening programmes. This will be a focus for the new LeDeR Team to ensure we have information on cancer screening to ensure equity and early identification to certain cancers for people with a learning disability and/or autism. There were 8 cancers reported to have been the cause of death - 2 were prostate, 2 pancreatic and the other cancers were of the bowel, brain, oesophagus and bladder.





Locality	Yes	No	Unclear	Grand Total
Croydon	12	4	0	16
Kingston	5	1	0	6
Merton	7	1	0	8
Richmond	6	1	1	8
Sutton	11	1	1	13
Wandsworth	12	2	1	15

Grand Total	**53**	**10**	**3**	**66**

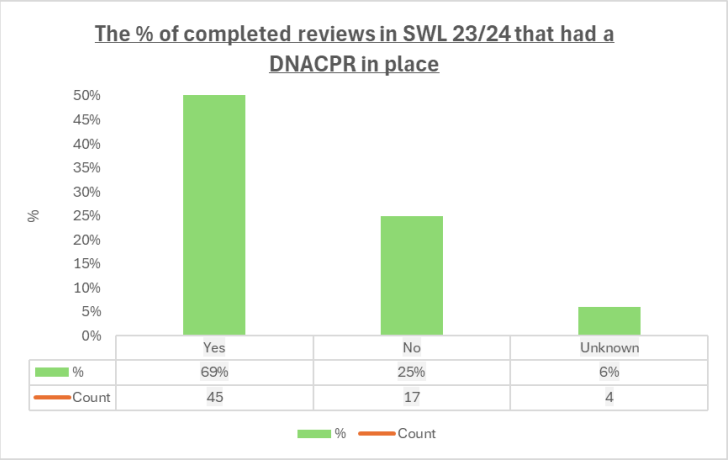
Annual health checks 2023 to 2024

11. End of life care

National LeDeR reviews have highlighted some issues for people with a learning disability and their families around informed choices for end-of-life care and decisions around any potential Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) recommendations

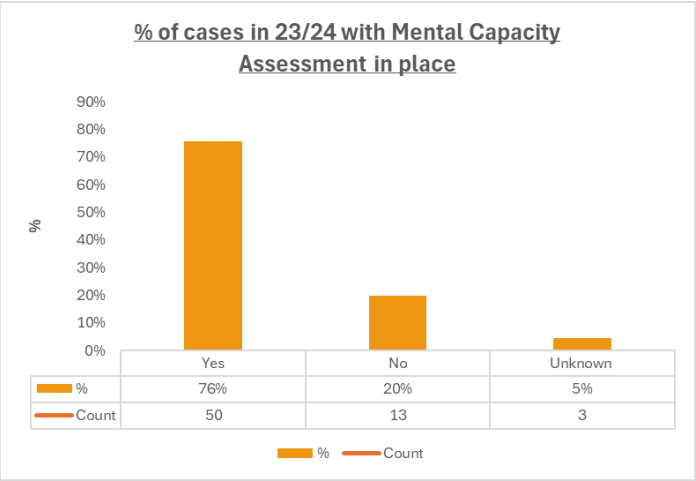
In SW London 62% of people (n-41) were on an End-of-Life Care Pathway, this allows for early planning and sensitive conversations around end-of-life care.

National LeDeR reviews showed that 71% of people had a 'Do Not Attempt Cardio- Pulmonary Resuscitation' order in place, this compares with 69% (n=45) in SW London and of those 95% (n=44) were completed correctly



12. Mental capacity decisions

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD, 2013) found poor adherence to the Mental Capacity Act 2005 in particular regarding assessments of capacity and the process of making 'Best Interest decisions. National LeDeR reviews report that 79% of people had a mental capacity decision documented. SW London reviews show that 76% (n=50) of people who needed an MCA had one and 86% of these were completed correctly

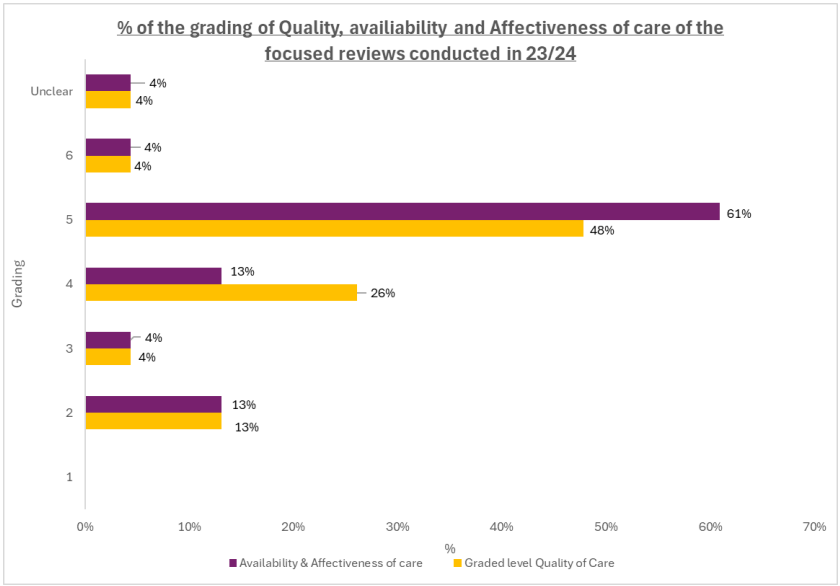


13. Grading of care

At the end of a focused review, reviewers are required to grade the care the person received. Care is graded on a scale of 1-6 where 1 represents poor care and 6 represents excellent care. Health and social care, has been reviewed on:

1. Quality of care the person received
2. Availability and effectiveness of services the person received

Some of the reasons that the care was graded low can be found in the learning from reviews.



14. Learning from reviews

These are key themes of positive practice and areas for learning and improvement identified from the 66 Completed LeDeR reviews. Quotes and examples have been included from review findings and families/ carers.

Top 6 Identified Themes for Positive Practice

1. Continuity and Flexibility of Services: GPs and hospitals made reasonable adjustments to accommodate patient and family needs which included home visits or virtual meetings.

   “GP service over the years managed health needs, longer appointments were given”, “The family overall were happy with care received by GP for past 26yrs”.” GP services were flexible in arranging home visit appointments.”

   “The community LD nurse liaised with the acute LD Nurse admission ensuring reasonable adjustments, for example to have fast tracked in A&E due to a long wait to avoid any distress”

   “Fantastic GP at the surgery – DR went out of their way to support visiting at home, taking time to explain things, offering to arrange taxi – it was this GP that managed to persuade to have bloods and tests about her wight loss, which led cancer diagnosis”

"GP was described as tremendous and amazing as well as the professionals they worked with in caring for family member"

2. Capacity Assessments and Sensitive Discussions: Thorough capacity assessments and sensitive discussions with families about End of life Care.

   "The acute LD nurse brought a printed copy of the hospital passport to A&E"

   "We were involved in his care planning and also his care in general. They participated in Decision making and our views were heard" - Family

3. Collaborative and Timely Referrals between professionals.: Prompt referrals to dieticians, adapting virtual meetings and providing support materials.

   "The hospital Learning disability teams across 3 hospitals worked well supporting family they were grateful for all the support xxx and family received from the LD/Mental health services"

4. Person-Centred Approach: Healthcare professionals ensured an enabling and person-centred approach to care.*The positives that should be taken from this review is that XXXX was free to have autonomy and make his own choices, which came with a degree of risk.

   "GP and Hospital care Person- centred care: The overall assessment of the quality of care provided and received met good practice standard"

   "Enabled to live a very independent life with autonomy"

5. Supportive Communication: Effective communication and collaboration between healthcare professionals and families. *There was good communication with the family and a culture of accountability evidenced in the Hospital notes. Mother reported the hospital was always very open/honest about illness and recovery.

   "The Next of Kin reported the care and stimulation XXXX received in the care home as excellent"

   "Next of Kin reported that person received very good care and treatment from services/professionals he encountered, and was treated with respect, dignity and kindness throughout interactions"

6. Individualized Care Plans: Customized care plans tailored to the specific needs of patients. *There was excellent joined up support from the care home, community, and

acute services, where discussions and co-ordination of care took place.. The person-centred care received and the overall assessment of the quality of care provided met good practice standard at all times was treated with dignity and respect

"Person was unable to tolerate blood testing. Through a programme of graded exposure and desensitisation, involving the Home Manager and carers – a successful blood test was undertaken"

Top 5 Identified Themes for Learning

1. Documentation Gaps: Lack of documented evidence for completed health actions, screenings and mental capacity decisions.
   - Formal mental capacity assessment was not done prior to consent for a procedure an incident report (Datix) was completed.
   - There was no evidence of mental capacity assessments for most decisions being made considering cognitive impairments

   "The Next of Kin advised if there was one thing to come out of LeDer reviews, it would be to make sure that all Annual Health Checks take place. Family felt that health issues may have been picked up/prevented if regular health checks had been received"

2. Need for Improved Communication: Improvement needed in communication between healthcare providers and family members, which included discussions around treatment options.
   - Reasonable adjustments should have been made by breast screening services to ensure equal access to this service. The care home reported difficulty in getting through to the hospital at times, not being provided with information, and the hospital not recognising that small care homes are family homes.

     "Family were not able to travel in the ambulance for a procedure and would have liked to have been allowed to avoid anxieties"

     "The next of kin did not feel they had always been kept up to date and informed"

     "Family felt the hospital communication could be improved around informing family/care homes when a person moves wards"

     "The key worker said that he often found the hospital passport would be easily discarded to one side, with no one taking on board the contents"

3. Inconsistent Service Delivery: Inconsistencies in service delivery across different

healthcare providers. (funding streams).

- There were difficulties encountered between the professionals and the challenges and tensions of boundaries/responsibilities between what health are responsible for and what social care are responsible for.

  “There was a lack of collaborative working between the safeguarding teams. Processes have to be put in place to follow through the clients and ensure that there is a clear process for the safeguarding teams to follow when they receive an out of borough referral.”

  “There needs to be early planning in accessing adult services and support should be given to families to help them navigate the transition process to adult services and advocacy support from voluntary groups”

4. Training Needs: Identified need for additional training for healthcare providers on handling specific patient needs.
   - The care home and GP need to be aware of DNAR status (when recorded on the hospital discharge summary) for people discharged from hospital. This should be reviewed in the community ensure it is still appropriate.

     “End of life care training could be offered to care homes or care providers”

     “there was an admission of care by the nursing staff to provide CPR as none of the staff were trained to perform it in a nursing home”

5. Confusion and Delay in Referral pathways: Delays in referring patients to specialists for further assessment and treatment.
   - Family report they were left to advocate for referrals alone and health professionals had not taken on board the seriousness of the decline in symptoms

     “There were delays in a move to adapted accommodation where having more space, adapted specifically to her needs, would have benefited”

     “Being registered as having a learning disability would have prompted an LD action plan"

15. Conclusion

In Summary, this report presents the findings from the Southwest London LeDeR Programme for 2023/24. The review of 88 notified deaths and 66 completed reviews highlighting both the achievements and challenges faced in addressing the health inequalities experienced by people with a learning disability and autism in Southwest London.

NHS South West London
Integrated Care Board

We must remember that LeDeR is about learning from the lives and deaths of people with a learning disability and/or autism. At the core of LeDeR programme are the people and their families, so our thanks go to the families, friends and carers of those who have died, for sharing their stories. We would also like to acknowledge the LeDeR Team of 2023/24 who worked with our health and social care stakeholders to ensure reviews were comprehensively completed in a timely manner, and it is their work which has been fundamental for this report.

SW London LeDeR programme is ever evolving and aspires to become a stronger advocate for people with a learning disability and autism . Mencap state " If you get it right for people with a learning disability then you can get it right for everyone" This stands true as people with a learning disability have the same health issues as anyone else but often face health inequalities. One of the significant outcomes of this report is the identification of themes, such as the high incidence of deaths from Aspiration Pneumonia, the predominance of hospital deaths, and the need for improved reporting, especially for autistic people. Despite these challenges, there has been notable progress on the increased and completion of Annual Health Checks, with SW London surpassing the national average, and the establishment of a new Quality Assurance Panel to ensure adherence to national LeDeR governance processes.

Normally, the SW London ICB would not release this report until the national LeDeR report is available. This timing allows for a comprehensive comparison and contrast at both local and national levels, incorporating feedback and data from partner organisations. Unfortunately, this has not been possible for the 2023/24 report, limiting the ability to provide a more thorough contextual analysis.

Moving forward, this report will be finalised and shared to solicit feedback from SW London ICB partners this is essential for driving improvements in care and addressing the disparities identified in this report.

The new SWL ICB LeDeR team are committed to continuing collaborative efforts with partners from the wider SW London Learning Disability and Autism network. We aim to gain insight into how priorities highlighted in this year's findings are being addressed. By doing so, the team aims to enhance the effectiveness of care and support the overarching goal of improving health outcomes for people with a learning disability and autism in Southwest London.