LEDER ANNUAL REPORT 2024–2025

LEARNING FROM THE LIVES AND DEATHS OF PEOPLE WITH LEARNING DISABILITIES AND AUTISTIC PEOPLE

September 2025

LeDeR Annual Report 2024–2025

CONTENTS

FORWARD

This year we carried out a review for John with the support of his sister. His sister shared the following information about John, his life and the profound impact that he had on his family. Significant people in the lives of those we conduct LeDeR reviews for are an invaluable part of the LeDeR process and we wanted to share these powerful words at the start of this report. This information has been shared with the consent of John's sister who wanted us to share his story. Some of his sister's words are below and the full text can be found in appendix 3.

'My Brother John'

'I recently lost my brother John at the age of 78. His death was quite unexpected so it came as a complete shock to me and the members of our family and indeed to all who knew him. You see John was a very special person.'

'My Dad was advised by a male member of my mother's family, that the best thing for all concerned was to 'put John away' then they could have a more 'normal' life. My dad was horrified at this suggestion and, together with my mother and his wonderful parents, became determined to do the very best they could to help John progress.'

'Mentally handicapped' people were not seen as being part of society in those days and now, with hindsight, that makes me feel very angry and thoroughly ashamed of peoples' attitudes.

'Although John was denied an education, he had developed many, many interests. He loved buses from a very early age, he loved music both pop and classical, he was fascinated by clocks and had his own wristwatch and later developed a keen interest in ferries.'

'When a disabled person enters a family, it obviously comes as a complete shock. Some people can cope well others just can't cope at all. It depends entirely on the individuals concerned. I can honestly say that John had a great deal of influence on many of our family members including me.'

'I will never really know if John was happy in his life but I like to believe he was. He would never dwell on 'bad' things, If he had not been well and you asked him how he was he would always answer "I'm better now" he never seemed or wanted to be unhappy.

Perhaps that's a lesson to us all!'

LeDeR Annual Report 2024–2025

1 EXECUTIVE SUMMARY

1.1 This report covers the period April 2024 – March 2025. There is an easy read summary of the report which can be found in Appendix 1. Additionally, a Makaton signed summary is available on our website.

1.2 Learning from the lives and deaths of people with Learning Disabilities and Autistic People (LeDeR) is a national service improvement programme that was set up with the aim of reducing health inequalities and preventing premature mortality by making changes to services both locally and nationally.

1.3 The aim of this report is to share learning from the LeDeR programme in Somerset in order to promote change across the health and social care system. This report will summarise what we have found out from the LeDeR reviews carried out in the reporting period, highlighting good practice and areas for improvement. It will discuss key themes that have emerged from reviews and highlight work the LeDeR team have already done with system partners to promote change and improve outcomes for people with learning disabilities and autistic people. Lastly, the report will identify key improvement priorities for the next year.

1.4 The report has been written by Dr Rachel Donne-Davis, Local Area Contact for the LeDeR Team and Lauren Newcombe, LeDeR Senior Reviewer. The LeDeR Team have provided case studies for the report. Discussions by the LeDeR Governance and Improvement Group have also been incorporated.

2 INTRODUCTION

National

2.1 LeDeR is a national service improvement programme looking at deaths of people with learning disabilities and autistic people. The programme was established in 2017 and is funded by NHS England (NHSE).

2.2 The LeDeR programme aims to achieve the following:

- Improve care for people with a learning disability and autistic people.
- Reduce health inequalities for people with a learning disability and autistic people.
- Prevent early deaths of people with a learning disability and autistic people.

2.3 Every adult with a learning disability (aged 18 and over) who dies, and every adult (aged 18 and over) with a diagnosis of autism, is eligible for a LeDeR review. Notifications of a death of someone with a learning disability or autistic people can be made by anyone through the LeDeR website https://leder.nhs.uk/

2.4 A LeDeR review takes a holistic approach, looking at key episodes of health and social care the person received that may have impacted on overall health outcomes. Key areas of improvement, as well as good practice, are identified for sharing across the system locally and nationally. Involving people who knew the person well is a key part of the process and care is taken to involve family members or others who knew the person so a pen portrait can be developed.

2.4 Every person with a learning disability that LeDeR are notified of will have an Initial Review. Reviewers will then use their professional judgement to determine whether a Focused Review (a more in-depth level of review) is required. Focused Reviews can also be requested by the family of the person who has died.

2.6 In certain situations, a Focused Review will automatically be carried out:

- Where the person is from a black, Asian or minority ethnic group.
- Where the person has a clinical diagnosis of autism but not a learning disability.
- Where the person has been in police custody in the last 5 years
- Where the person had been under a Mental Health Act restriction in the last 5 years
- Local priority areas for focused reviews can also be identified. We currently don’t have any priority areas in Somerset as these have been stood down. However, if any themes emerge in the data going forward we can identify priority areas at that stage.

Local

2.7 Within NHS Somerset, the LeDeR Team sits within the Quality Improvement and Patient Safety Directorate. The LeDeR Team consists of a Local Area Contact (LAC), Senior reviewer, Two reviewers and two team administrators. The Chief Nursing Officer for NHS Somerset is the Senior Responsible Officer (SRO) for LeDeR.

2.8 In 2023-24 we identified the following improvement priority areas:

- Patient Engagement
- The Mental Capacity Act
- End of Life Care
- Implement recommendations from the review into respiratory deaths
- Complete review into sepsis deaths

2.9 This report will update on service improvement work related to these priorities and identify new priority areas as highlighted in LeDeR reviews in 2024–2025.

2.10 In the LeDeR programme locally, we are privileged to work with a range of system partners to quality assure our reviews and ensure that learning is translated into action. In the following pages we share some of the views of people involved in the LeDeR programme.

“In my role of SRO for this vital area of work, the LeDeR process continues to enable us to learn as a system. This year we have seen a continued focus on taking action where improvement is required, evaluating the effectiveness of the actions we have taken and importantly learning from areas of good practice. Our commitment to learning from individual experiences of the care and support we provide, and improving the outcomes for our population remains a priority”

Shelagh Meldrum, LeDeR SRO and Chief Nursing Officer & Director of Operations, NHS Somerset.

“ A 2023 LeDeR audit identified that improvements were needed in advance care planning conversations for people with learning disabilities. With support from LeDeR throughout, we were able to engage in a Somerset Foundation Trust Gold Quality Improvement project, using a proven methodology to have discussions with people with learning disabilities (and their families) about their future and end of life care wishes in a safe and inclusive way. LeDeR encouraged the project and helped us to spread the learning to others across the county. The benefits of the project exceeded the initial outcomes and has led to creation of advance statements and Somerset Treatment Escalation Plans, which are saved on Somerset shared digital system (SIDeR+) Newly developed printable easy read resources have also been created.
Working with LeDeR has been incredibly positive and it is clear that their aim is to improve outcomes and healthcare for people with learning disabilities in Somerset.”

Amy Giles
Advance Care Planning Lead, Somerset Foundation Trust

“The LeDeR work continues to provide valuable insights into the health and care of people with learning disabilities and autistic people in Somerset.

Over the last year LeDeR has continued to work alongside other partners providing care to people with learning disabilities and autistic people in Somerset, using the learning from their reviews to identity and implement changes to improve our services. The aim continues to be to reduce the historic health inequalities experienced by this community. The focus this year has been on improving care planning, end of life care and access to audiology services. The team have also been taking opportunities to promote joint working between mainstream and specialist therapy teams, together with improving the implementation of the Mental Capacity Act

With the renewed focus on population health and reducing health inequalities in the NHS 10 year plan, LeDeR continues to celebrate what works well and what can be improved for people with learning disabilities and autistic people accessing our health and care system. I would commend this report to you and encourage you to take a moment to read it and reflect on the progress made over the past year.”

Jonathan Higman, Chief Executive NHS Somerset.

Patient Engagement

2.11 Meaningful engagement of people with learning disabilities and autistic people is key to LeDeR being effective as a service improvement tool. This is an area we have been working on; we have made some improvements but are keen to develop this further.

2.12 We have continued to work with Biggerhouse Film and My Day Care to share about people's experiences and encourage people to have conversations with people with learning disabilities and autistic people about death and dying. We have shared the film 'we need to talk about…death' and run workshops in a variety of contexts including the key note presentation at the Somerset End of Life Care Education Conference in March. We are particularly grateful to the students from My Day Services for sharing their experiences with us in the film and at these events and informing our way of working.

2.13 It is important to remember that this report is about the deaths of people with learning disabilities and autistic people. Whilst the case studies and data are anonymised, these are real people's stories. Their lives were important and of significant value and the impact their deaths have had on their family and loved ones will doubtless be substantial.

2.14 We would like to thank families and carers who have taken the time to speak to us during what has often been a really difficult time in their lives. Their contribution to this process has been invaluable and we feel privileged to share part of their story.

Quality Assurance and Governance

2.15 All LeDeR reviews in Somerset are quality assured via peer review and signed off by a combination of the LeDeR LAC, Senior Reviewer and another relevant health care professionals. Additionally, Focused Reviews are further approved by a Focused Review Panel which is a subgroup of the LeDeR Governance and Improvement Group. The LeDeR Governance and Improvement group has representation from across the Somerset system. This includes health, social care, family carer and voluntary sector representation. This group reports to the ICB Quality Committee and NHS Somerset Board as needed.

3 LEARNING FROM DEATHS IN SOMERSET

Notifications

3.1 41 notifications were received between April 2024 – March 2025. Of the 41 notifications, three were out of scope for the LeDeR programme. Six were for people with a standalone diagnosis of autism. There were 30 notifications for people with learning disabilities and two were for autistic people who also had a learning disability. Chart 1 details the frequency of notifications across the reporting period. Chart 2 illustrates where the notifications came from. It is encouraging to see more notifications coming from the person's usual place of residence than in previous years.

Chart 1

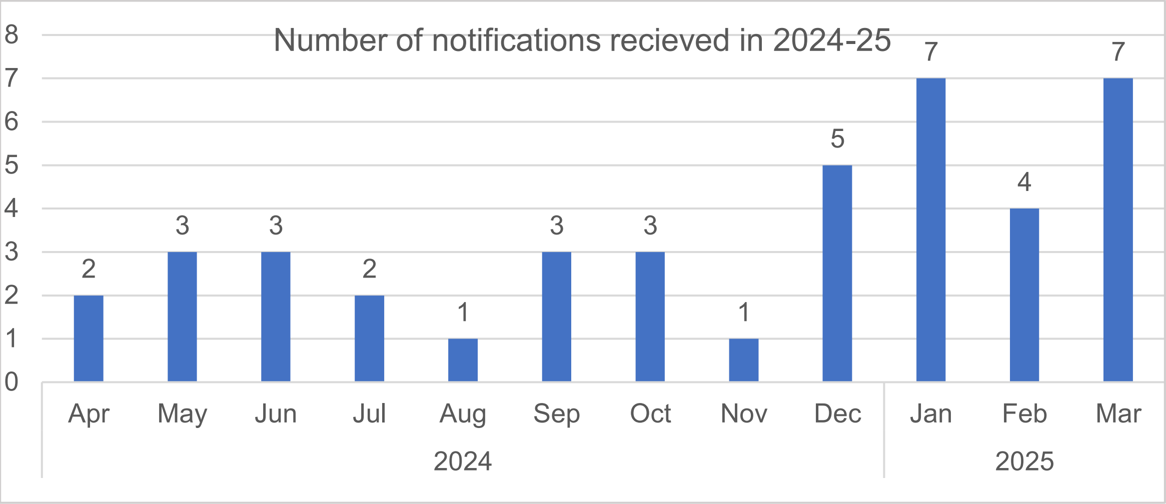
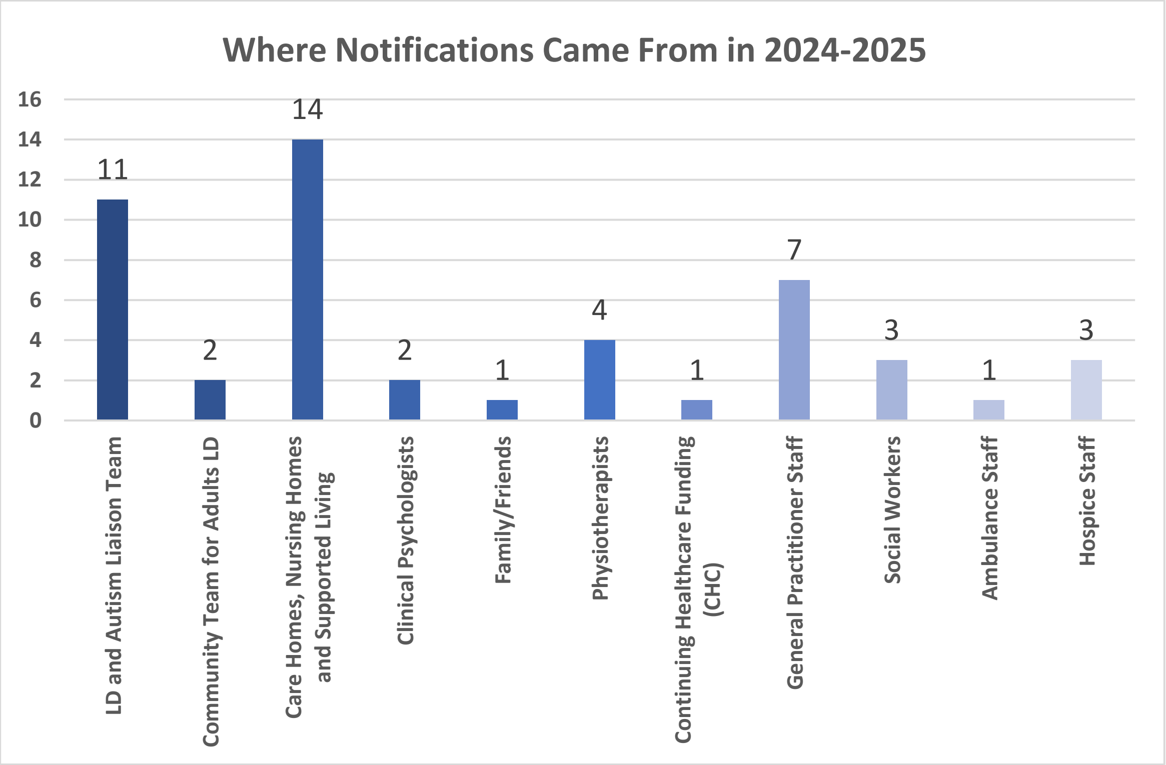


Chart 2



Autism Reviews

3.2 During the reporting period, we received six notifications relating to the deaths of autistic people.

3.3 This represents an increase in the number of notifications we are receiving for autistic people from the previous reporting period. However we are still receiving a relatively small number of notifications and therefore have to be careful about making generalisations from the data. Further information on the learning generated from Autism reviews in the reporting period can be found in our learning into action section.

Completed Reviews in 2024–2025

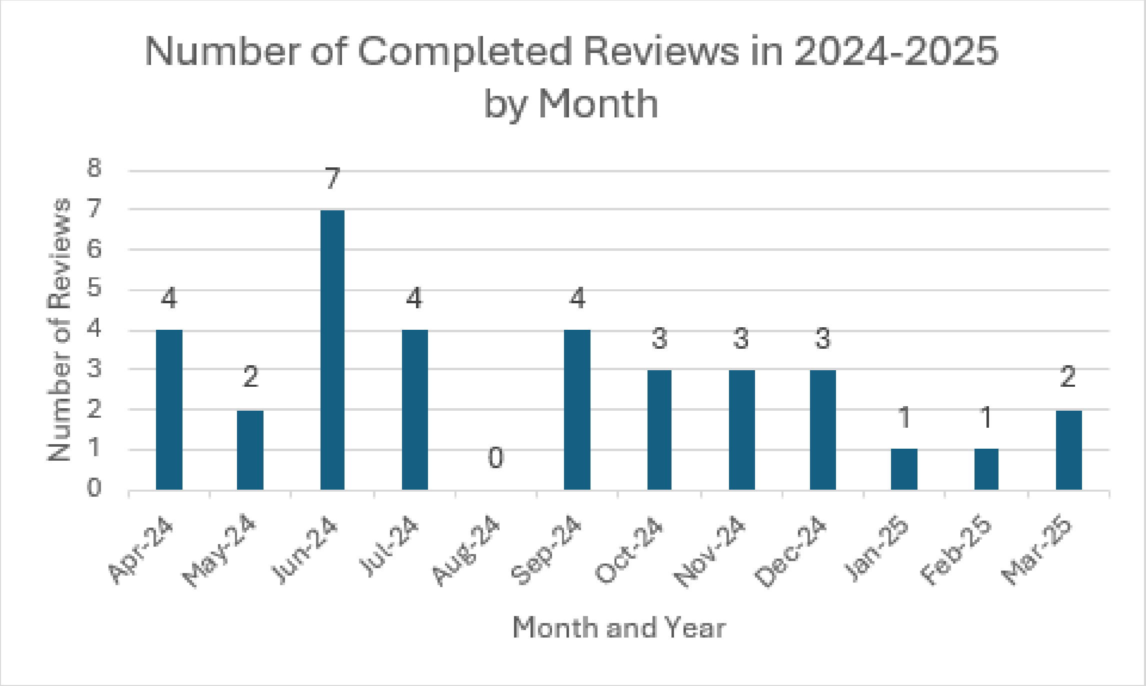
3.4 There were 34 reviews completed in the reporting period. Of these, 19 were Focused Reviews. Chart 3 shows the distribution of these across the reporting period.

3.5 NHSE suggest that a minimum of 35% of reviews should be Focused. We continue to perform in line with that with 55% of Somerset reviews being focused.

3.6 Of the 19 focused reviews there were:

- 3 for autistic people
- 12 for people with a learning disability
- 4 for autistic people who also had a learning disability.

Chart 3



Key Performance Indicators

3.7 NHSE sets two key performance indicators (KPI) for LeDeR teams:

- That all notifications will be allocated within three months of receipt.
- That all reviews will be completed within six months of notification.

3.8 Of the 34 reviews completed in the reporting period, all were allocated within three months of notification.

3.9 28 reviews were completed within six months of notification. The 6 reviews that missed the KPI deadline did so for the following reasons:

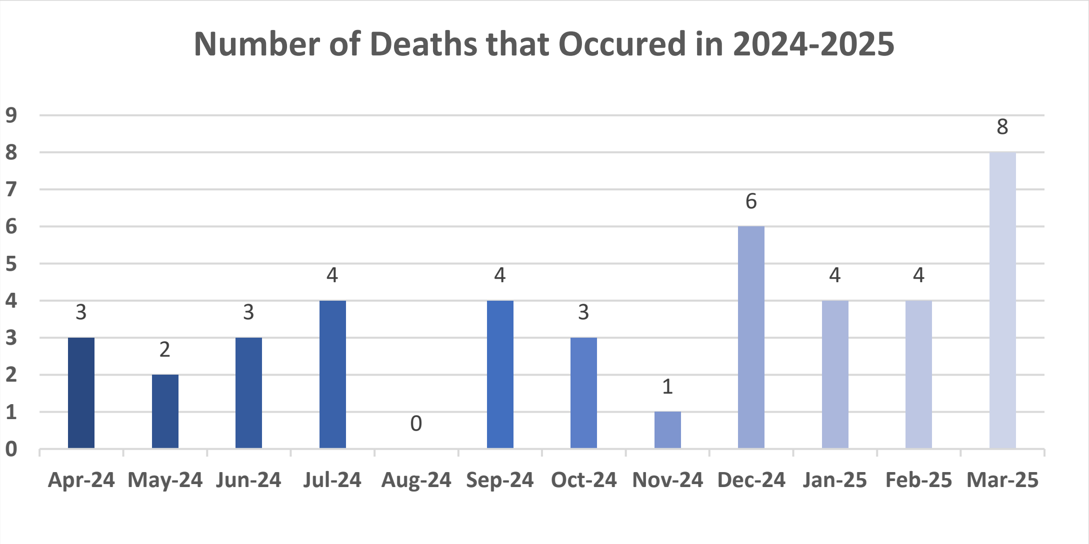
- 1 missed the KPI by 4 days
- 1 was due to a delay in receiving GP notes
- 1 was allow time for meaningful input from the family
- 1 was due to the review needing to be discussed at a second panel meeting
- 2 were due to complexity of information needed prior to going to panel.

About People Who Died

3.10 The following demographic information is based on date of death as opposed to date of review completion or date notification was received. This brings our reporting in line with national data analysis and allows for more timely learning from deaths. 42 deaths occurred during the reporting period and these are detailed in Chart 4. Of the 42 deaths that occurred:

- 3 were not eligible for LeDeR and marked as 'out of scope'
- 6 were deaths of autistic people
- 25 were deaths of people with learning disabilities
- 3 were deaths of autistic people who also had learning disabilities
- 5 are still tbc due to being in progress or on hold

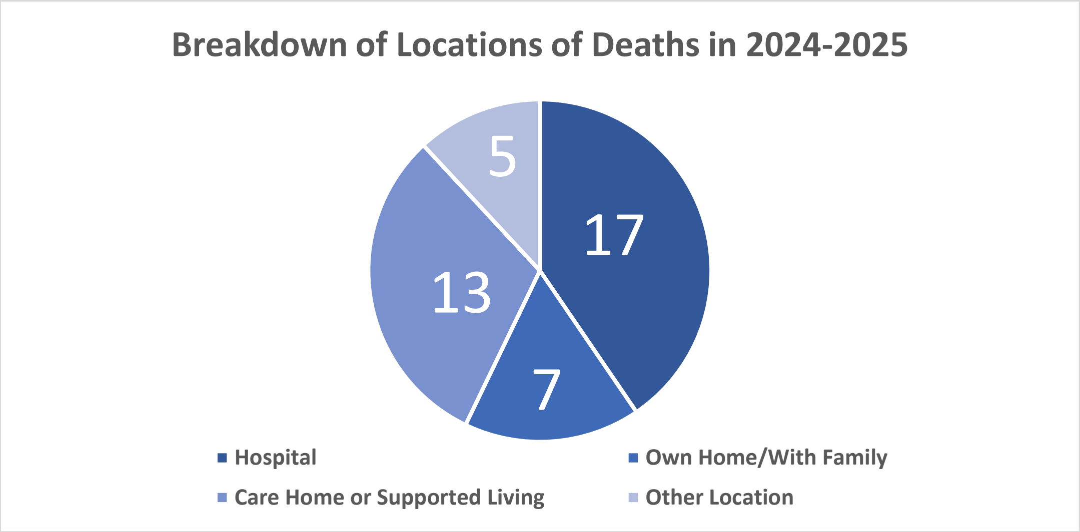
Chart 4



Place of Death

3.11 Similarly to the previous reporting period the highest number of deaths occurred in a hospital setting. This is in line with national findings which reported that 57% of deaths occurred in a hospital setting(*1). Of the 5 deaths that occurred in 'other locations' 2 occurred in a hospice setting and 3 are unknown/can't be published due to other statutory investigations.

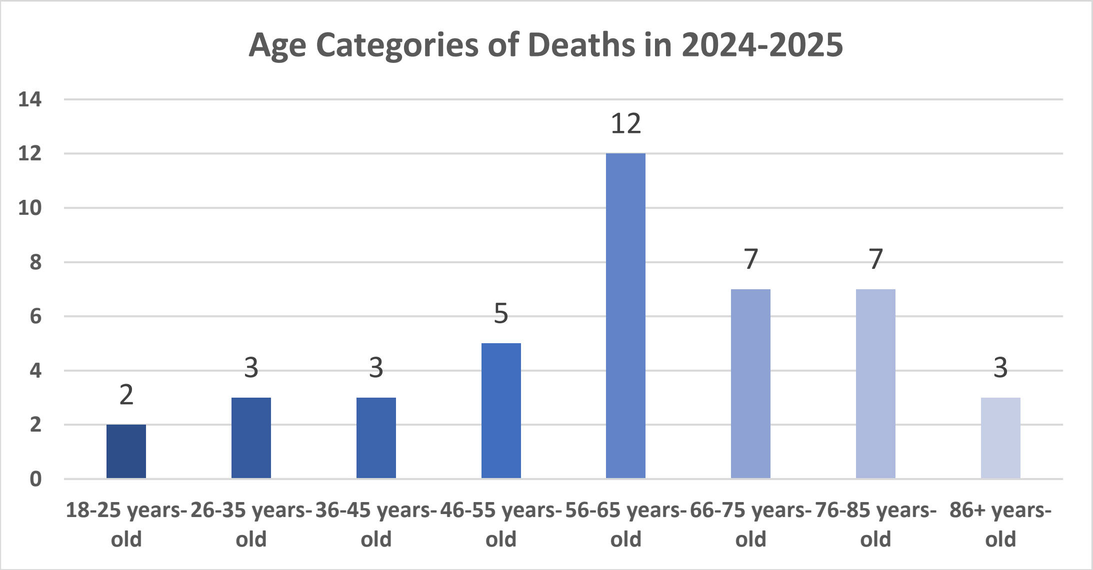
Chart 5



Age at Death

3.12 The highest proportion of deaths occurred in the 56-65 range. This is detailed in Chart 6 and does not reflect a significant change on previous year's data. It mirrors the data presented in the national LeDeR data (*1). The youngest person who died was 18 year old and the oldest person was 100 years old.

Chart 6



Gender

3.13 Of the 42 deaths that occurred in the reporting period, 26 were for people who identified as male and 16 were for people who identified as female.

Ethnicity

3.14 Of the 42 deaths in the reporting period, 40 were for people whose ethnicity was recorded as white British. One individual's ethnicity was recorded as Bangladeshi and Muslim and for one review their ethnicity was unknown.

3.15 The 2021 census (*2) indicated that in Somerset 91.3% of the population would describe themselves as White British. Whilst LeDeR data from the current reporting period does not differ significantly from this it is important to interpret ethnicity data with caution due to the small numbers involved.

Cause of Death

3.16 Chart 7 details the main Cause of Death as grouped by International Classification of Disease (ICD-10) chapter codes for each death in the reporting period.

3.17 The ICD-10 is a standardised tool used to code and understand medical conditions and causes of death. Grouping the data in this way brings us in line with the national LeDeR report and allows for ease of data analysis.

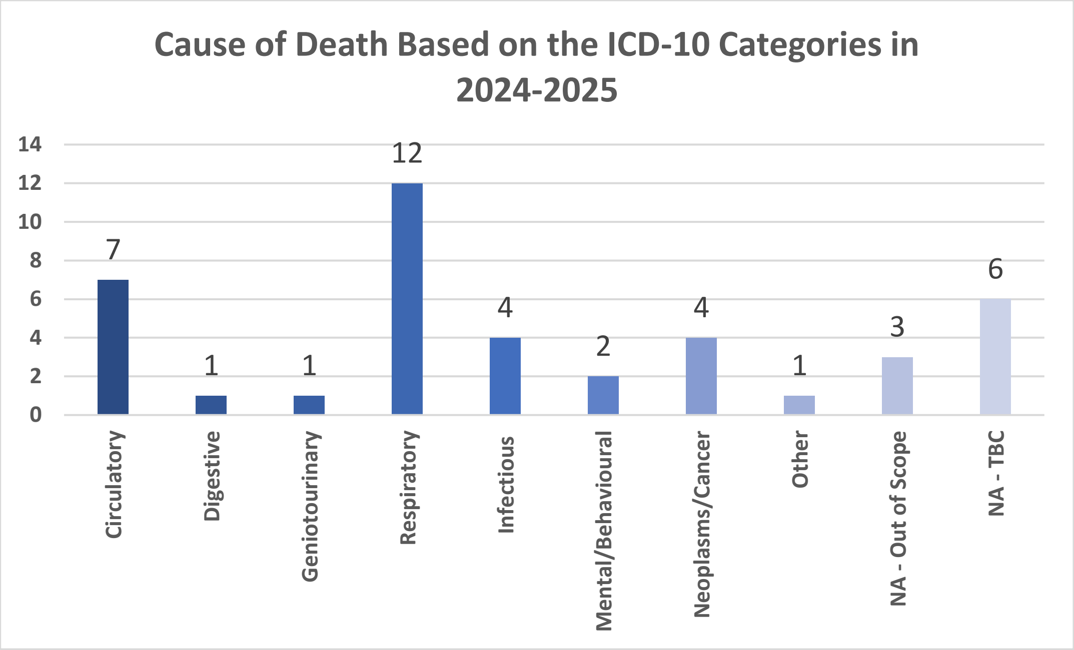
3.18 The cause of death data from 2024–2025 is similar to that of the previous reporting period with 'diseases of the respiratory system' being the most commonly recorded cause of death. The next most common cause of 'death recorded was 'diseases of the circulatory system' (seven deaths). Four deaths were coded as being related to infectious and/or parasitic diseases which is comparable with the previous reporting period.

3.19 There was 1 death where Sudden Unexpected Death in Epilepsy (SUDEP) was indicated as the primary cause of death. A Focused Review was carried out of this death. Learning was identified related to mode of medication administration and the importance of communicating effectively with people who knew the individual well, e.g. care and support staff.

3.20 The local data closely mirrors national data. The most recently available national data also indicated 'diseases of the circulatory system' and 'diseases of the respiratory system' as commonly reported causes of death based on ICD-10 chapter codes (*3).

3.21 Regarding respiratory deaths we will continue to carry out Focused Reviews of respiratory deaths where significant learning is indicated.

Chart 7



4 PEOPLES' STORIES

4.1 At the heart of LeDeR are people - real people with real stories and we are uniquely privileged to be able to hear these stories and learn from them as we conduct LeDeR reviews. Spending time with family members and other people important to the person who died gives us a unique insight into that person. We are so grateful to all the people who have given their time to speak to us. Below are just a few examples of some of the stories we have had the privilege of hearing as a team. The stories highlight areas of both good practice and areas for improvement. Names and other identifiable details have been changed to enable the stories to be shared anonymously.

Alison's Story

4.2 Alison was a lady in her 50's who had lived her early years in a large, long-stay hospital setting. She had moved out into the community when the hospitals closed. She had lived near her family who played an active part in her life, either visiting her or talking to her on the telephone most days. She often had visits home with her family too. Alison had Cerebral Palsy and was described as having a 'profound' learning disability. She was dependent on others for all her care needs and mobility. She did not use speech but people who knew her well understood her communication. She had a great sense of humour and enjoyed music, trips to the park and holidays. She had epilepsy, asthma and osteoporosis. She also had dysphagia and suffered from recurrent chest infections which often meant she had prolonged and frequent stays at the local acute hospital. She had proactive input from Physiotherapy and Speech and Language Therapy from the Community Team for Adults with Learning Disabilities to help to reduce risks when eating and drinking and in optimising her respiratory health. Her death occurred suddenly at home following a heart attack. The heart issue would have been difficult to detect as she did not display any signs or symptoms that would have prompted investigations. The family and carers reported that the response from emergency services had been excellent. The aftercare and support from services was reported as being extremely helpful and caring. Though Alison's death was sudden, the review told a positive story, highlighting good health and social care input throughout her life.

Arthur's Story

4.3 Arthur was a gentleman with a moderate learning disability and significant medical needs who died of 'old age'. He had several medical conditions which required regular monitoring and management through medication. Arthur was an avid supporter of his local football club and was a well-known face in the community where he lived. Arthur was a resident in his supported living provision for 44 years. During this time, the care staff became very familiar with him, his personality, likes and dislikes. He created strong relationships with staff members who were consistent and present in regularly providing care and support to him. The care staff responded to changes in his health and sought input from the relevant teams when needed. The care staff felt that it was important for him to have consistent staff who could build a rapport with him. The home manager commented that the GP was also very good at providing him with consistent input so that he received personalised care and support. The care providers' ability to recognise and respond to needs and changes in presentation meant that he was able to receive responsive care at his home until his death. He had always been clear about his dislike for hospitals and his desire to remain at home for as long as possible. This was facilitated by care providers requesting an assessment and receiving funding to continue to support him and his increasing medical needs. The consistent and personalised care meant that he could live a long and fulfilled life. Arthur's story highlights the benefits of consistency and finding the right home and support to allow people to receive the best possible care both during and at the end of their lives.

Fred's Story

4.4 Fred had a diagnosis of Down's Syndrome and moved into a long-stay hospital as a child, before moving to a supported living setting 20 years later. He had contact with his mother until she died and was in contact with his sister. Fred communicated with some words and also used pictures, he could read odd words. He loved writing with pens in a notebook and enjoyed listening to music. In the past when he was more able, he enjoyed dancing, karaoke, helping with cooking, walking, and activities such as bowling and mowing the lawn. He liked gardening and going to a garden centre to choose plants. He was described as a 'gentle soul'. He could be quite anxious at times, and it was felt that some of his behaviours may have been related to his experiences during the long period of institutional care in his early life. Fred's last years were very difficult for him. He was diagnosed with dementia and then suffered a hip fracture and became immobile. Two years prior to his death he sustained multiple fractures following seizures and spent long periods of time in hospital. He also had pressure ulcers and a contracture of his leg. He moved to a nursing home for the last few months of his life. The review highlighted issues regarding a lack of timely diagnosis of osteoporosis. Earlier diagnosis and treatment may have reduced the likelihood or severity of subsequent fractures he experienced. His leg contracture had a negative impact on his overall wellbeing and also exacerbated pressure ulcers, and he experienced considerable pain. He would have benefited from earlier input from physiotherapy as there were significant benefits once this was started. Fred died of pneumonia in his nursing home.

Ryan's Story

4.5 Ryan was an autistic man who had been diagnosed late in life, less than a year before he died. He lived independently for his adult life, renting various properties and driving. He worked for nine years at a workplace which gave him an incredible network of support. This was particularly valuable to him as he was estranged from his family. He began to experience headaches, and his colleagues advised him to seek support from the GP for his new symptoms as he did not have a history of ever mentioning physical ailments. Following his colleagues contacting the GP with his permission to detail concerns around a change in behaviour, he was referred for a CT scan and MRI scan which discovered a Glioblastoma (a type of cancer that starts as a growth of cells in the brain or spinal cord) which unfortunately would not benefit from active treatment. He was put on the end-of-life pathway to receive palliative care and a fast track CHC application was made. Ryan moved into a nursing home where he received frequent visits from his colleagues and died shortly afterwards. A plaque has been put up at his workplace, to recognise his significance within the 'work family'. The review was an example of how autistic people may have altered responsivity to pain and altered perceptions of time and how the failure to consider how autism may affect these could hinder accurate and timely diagnosis and treatment. The review also found that Ryan may have benefitted from increased support to access services for substance misuse. It was felt that a health/hospital passport would have been useful to help him to communicate his needs to health professionals. Ryan's colleagues were highly commended by the LeDeR Quality Assurance Panel who felt they demonstrated a good example of how "simple it is to put in place decent, good, honest reasonable adjustments" that "cost nothing but empathy."

5 LEARNING INTO ACTION

5.1 LeDeR is a service improvement programme so ensuring that learning from reviews leads to changes in practice locally is at the core of what the programme is trying to deliver in Somerset.

Update on Learning into Action

5.2 The following is a summary of what has been achieved across the Somerset system against the service improvement priorities identified in our last annual report. We have used the image of jigsaw puzzle pieces as it is only when these developments work together that they are truly effective in improving outcomes for people with a learning disability and autistic people.

5.3 In addition to the overview there is further information provided on our review into sepsis deaths, learning from the 3 completed reviews related to the deaths of autistic people and the work we have carried out in relation to the Mental Capacity Act (MCA).

Patient Engagement

We have met with experts by experience elsewhere in the region to find out how they are involved in the LeDeR process and to observe their quality assurance panels.

We have worked with experts by experience to discuss the best ways to talk about death and dying. We have shared these discussions at conferences and workshops.

Our Governance and Improvement group has a membership which includes our local parent carer forum.

We have funded and enabled engagement with experts by experience on specific service improvement projects

The Mental Capacity Act (MCA)

Reviewed and streamlined the MCA competency framework to make it easier for clinicians to use in practice.

Ran training and supervision sessions to share LeDeR learning related to MCA implementation.

Worked with providers to establish a MCA Learning Disability Liaison Nurse post.

Worked with providers to develop a more robust care pathway for Best Interest Considerations for patients who lack capacity on the Colorectal pathway.

End of Life Care

Agreement reached about use of patient deterioration tool in the community as well as access to training for care staff.

Additional ‘no barriers here’ training delivered in Somerset with support from the EOL care education team.

We gave the key note lecture at the Somerset End of Life Care Conference highlighting the importance of proactive conversations about death, dying and bereavement.

Ongoing work to implement Treatment Escalation Plans in Somerset. Electronic Treatment Escalation Plans have been launched. Audit plan developed and audit to be carried out in 2025/26.

Respiratory Death Recommendations

Recommendations related to Treatment Escalation Plans and recognizing patient deterioration have been implemented.

Further facilitators have been trained in the ‘no barriers here’ approach to Advance Care Planning

Further work is needed regarding vaccination uptake in high risk groups within the LD population.

Communication with Key Stakeholders

5.4 In addition to the above we have also worked hard to raise the profile of LeDeR and share LeDeR learning to inform best practice in the following ways:

- Shared a range of case studies from LeDeR reviews to inform clinical practice
- Published a learning brief on contractures
- Ran a series of events in LD awareness week
- Shared outcomes of LeDeR related audit at national conferences
- Shared information on key topics including menopause, oral health and staying safe
- Provided ongoing training and support for LD champions in primary care

Learning Into Action: Sepsis Deaths

5.5 As an outcome of our previous annual report, we carried out a deep dive into the five sepsis cases that occurred in 2023/24. The full report can be viewed in Appendix 2, but a summary of the findings and relevant recommendations can be found below.

Recommendations

5.6 The following recommendations were made:

- Raising awareness – We will liaise with our Infection Control colleagues to create/share information with people with learning disabilities and their carers in Somerset about sepsis and the signs and symptoms. Information should highlight common factors and vulnerabilities evidenced from the reviews above and from the review of current evidence e.g. dysphagia, frailty, gastrointestinal conditions, communication difficulties.

- Alongside communications about sepsis, the LeDeR team will hold an accessible Lunchtime Learning session on sepsis with support from the Infection Control team. This will be available to our network of LD Champions, but attendance can also be widened and offered to people with learning disabilities and their carers via the local carers' network.

- We will work with our vaccination team to increase the uptake of pneumococcal vaccines in high-risk groups within the learning disability population.

- We will continue to promote the use of patient deterioration tools and signpost to these in our communications and learning session.

Learning into Action: The Mental Capacity Act

5.7 Several key themes relating to the Mental Capacity Act (MCA) became apparent through LeDeR reviews in 2023/24 and continue to be reflected in LeDeR reviews in 2024–2025. There is a summary of work that has been carried out to date in the infographic above.

5.8 There continues to be difficulties evidenced in translating the knowledge acquired through formal training to the skills required to undertake activity related to the assessment of mental capacity and the consideration of Best Interests. Research indicates (*4) that conventional training is useful in respect of raising awareness of the legislation, rather than preparing staff to navigate it. Over the next year we would like to explore adjuncts to training including:

i) development of capacity and best templates for different domains of decision making.
ii) use of recently reviewed Mental Capacity Competency Framework to structure support offered to clinicians post training.
iii) explore practice based training models in which inexperienced staff are supported directly by experienced colleagues in MCA work.

Learning into Action: Autism Reviews

5.9 In 2022, LeDeR began receiving notifications of deaths of adults (aged 18 and over) with a diagnosis of autism (without a learning disability) in England. Previously, autistic adults were only included where they had a learning disability.

5.10 Locally we are still receiving a relatively small number of notifications related to deaths of people with a stand-alone diagnosis of autism, although this is slowly increasing. This reflects the national picture. According to national data, in 2023, the deaths of only 173 autistic adults without a learning disability were notified to LeDeR. The number of notifications suggests that only a minority of deaths of autistic adults are currently being reported to LeDeR. We are working locally to increase the awareness of LeDeR with autistic people and services that support them.

5.11 During the reporting period, we received six notifications of the deaths of autistic people, compared with one notification in the previous reporting period. We completed three reviews for autistic people in the reporting period, one of which was received in 2022/23. Two reviews remain on hold awaiting the outcome of other statutory processes. Additionally, one review was completed in July 2025, outside of the reporting period and will be included in data in a future report.

Themes

5.12 It is important to keep in mind that the LeDeR reviews of deaths of autistic adults discussed below are unlikely to be fully representative of the deaths of autistic adults in Somerset. Due to the small number of reviews completed, it would not be useful to compare and comment on demographic data. It is useful however to start to draw out emergent themes to help to inform areas for service improvement going forward.

National Themes

5.13 National data published in the 2023 Annual Report found the following themes relating to issues with the quality of care for autistic people:

1. A lack of high-quality training, awareness, or understanding of the specific needs of autistic people.
2. A lack of services specifically tailored to the needs of an autistic adult, or a lack of support to access services.
3. Failing to recognise that significant changes to an individual's situation can prove more challenging for an autistic individual than for someone who is not autistic.
4. Difficulty transitioning from child to adult services
5. A lack of crisis escalation plans, and/or a lack of an awareness of suicidality risk for autistic adults.
6. A lack of communication between support networks and a lack of multidisciplinary collaboration.
7. Missed or delayed diagnosis of physical health conditions due to wrongly attributing symptoms to autism (diagnostic overshadowing).

Local Themes

5.14 The three reviews for autistic people completed in Somerset found the following themes:

- Two of the reviews highlighted that late diagnosis of autism meant that the people’s needs were not adequately met or behaviour fully understood. Earlier diagnosis would also have helped health and care professionals to better understand their needs and any reasonable adjustments that may have been beneficial. It was also felt that earlier diagnosis would have helped them to better understand their own strengths and needs. For both individuals there were missed opportunities for earlier diagnosis.

- One review found that sufficient recognition was not given to the impact of the person's autism by services. This likely impacted on the services’ ability to meet their needs effectively. Care by a Mental Health Service was rated ‘poor’ following a Structured Judgement Review (SJR). Discharge planning and onwards care did not appear to have been considered and may have led to the person feeling unsure about future care provision. It was also noted that the SJR did not acknowledge the person's autism (beyond it being recorded as a diagnosis) and how this may have impacted on them.

- One review found missed opportunities for onward referral to the Eating Disorder Service.

- One review found a lack of evidence that reasonable adjustments were always considered to meet the person’s needs. The person had a dual diagnosis of mental health conditions and chronic alcohol dependency. This may have contributed to the person not following medical advice given and taking prescribed medication.

- One review found the person benefitted from being able to build relationships and receive consistent input from health and social care professionals. However, there was a lack of evidence that this was provided across all services.

- One review highlighted that the person may have benefitted from having an Autism Health Passport to let people know about their needs and reduce the need for them to have to give information verbally during times of distress. It was recognised that it is not widely known that Health Passports are available and may be of benefit to autistic people.

Learning into Action

5.15 We have shared learning from autism reviews with relevant commissioners at the ICB to highlight how the current diagnostic services in Somerset have limited resources and a growing waiting list. We have also raised the current lack of specialist liaison services for autistic people in acute settings.

5.16 We have continued to promote both the Oliver McGowan Mandatory Training and Somerset Autism Spectrum Service.

5.17 One of the reviews was prepared as a case study for training purposes. It was shared across the system to highlight the issues that the person experienced and the support currently available for autistic people and professionals in Somerset.

5.18 We have linked with the Somerset Autism Spectrum Service to share information and templates for Health Passports for autistic people across the system.

Learning into Action: Plans for the Future

5.19 Based on key themes coming out of LeDeR reviews in 2024-2025, learning from other sources such as Safeguarding Adults Reviews, and specific discussions at the LeDeR Governance and Improvement Group, we intend to focus on the following areas of work in 2025-26.

- We acknowledge that our work with experts by experience has not improved as much as we would like. We intend to do more to work with experts by experience in 2025-26 so that they can more directly inform the work of the LeDeR programme.

- Learning from both the sepsis and respiratory deep dives highlights the importance of access to appropriate vaccinations for people with learning disabilities. We intend to work with our colleagues in the vaccination team to promote this in an accessible way.
- We want to increase our understanding of the barriers related to the use of autism passports. We plan to work with key stakeholders to carry out a scoping exercise and develop some recommendations to improve uptake locally.
- We want to work with services locally who are working with vulnerable population groups, to increase awareness of LeDeR.
- We will continue to work with colleagues in strategic commissioning to share LeDeR learning and inform best practice e.g. provision of specialist epilepsy services for people with learning disabilities.
- We will continue to work with colleagues in the acute sector to support service improvement projects and ensure that people with LD and autistic people have positive experiences in that setting.
- We will support service improvement projects related to LD Annual Health Checks.
- We will work to streamline our review processes so that we are able to prioritise service improvement.

5.20 Additionally, we will carry out the recommendations from the review into sepsis deaths and the work identified in 5.8 as part of the MCA workstream.

6 CONCLUSIONS

6.1 2024-2025 has been a productive time for LeDeR in Somerset. Despite significant changes and challenges across the health and care sector LeDeR has continued to work to implement meaningful change for people with learning disabilities and autistic people.

6.2 We recognise there are areas that due to system pressures we did not make as much progress as we would have liked. These areas are reflected in our learning into action priorities for 2025-26 and we intend to create additional capacity within our review process to be able to prioritise these.

6.3 Alison, Arthur, Fred and Ryan’s stories whilst highlighting some positive practice, emphasize the need for LeDeR to continue to raise awareness of health inequalities and improve outcomes for people with learning disabilities and autistic people in Somerset.

References

1) Kings College London (2023) Learning from Lives and Deaths – people with a learning disability and autistic people.

2) Census (2021) TSO30

3) White, A; Sheehan, R; Ditzel, N; Ding, J; Roberts, C; Magill, N; Yu, MKL; Keagan-Bull, R; Chauhan, U; Tuffrey-Wijne, I; Strydom, A (2024). Learning from Lives and Deaths - People with a learning disability and autistic people (LeDeR) report for 2023. LeDeR Autism and Learning Disability partnership, King's College London

4) Willner, P., Bridle, J., Price, V., Dymond, S. & Lewis, G. 2013, "What do NHS staff learn from training on the Mental Capacity Act (2005)?", Legal and criminological psychology, vol. 18, no. 1, pp. 83–101.

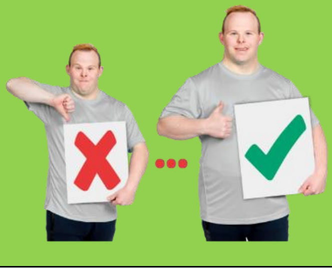
APPENDIX I – Easy Read Summary

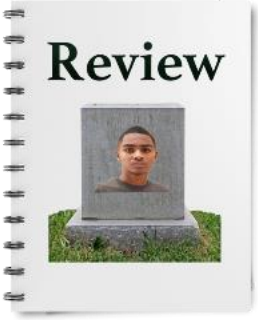
LEDER ANNUAL REPORT

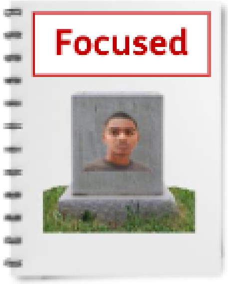
APRIL 2024 – MARCH 2025

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

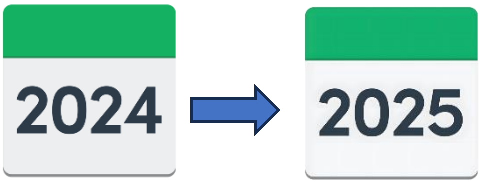
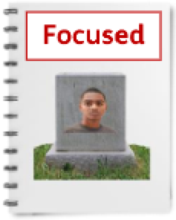
made with photosymbols®

	1. About our report
	2. The people who died
	3. People's stories
	4. What we have done to make care better
	5. What we are going to do next
	6. Useful information

	**1. About our report**
	We shared some information about **John**. His sister helped us to write his review. **John was very important to his family and made their lives better.**
	The LeDeR Team find out about the care and support given to adults with a learning disability and autistic people who have died in Somerset. This is called a **LeDeR review**.
	A **LeDeR review** looks at what care was **good** for the person who died.
	The **LeDeR review** looks at **what could have been done better** for the person who died.

	We talk to the people who knew the person who died, like their **family** and **carers.**
	**Initial Review** Every death which is reported to the LeDeR team gets an **initial review**.
	**Focused Review** **Focused reviews** are more detailed. We find out more information about the person's care and support.
	**Reasons for a Focused Review:** - the person was from a **Black, Asian or minority ethnic background** - the person was **autistic**, but did not have a learning disability - the person had been in **police custody** in the last 5 years - the person had been under a **Mental Health Act restriction** in the last 5 years. - their **family** ask for a focused review

	All LeDeR reviews are **checked** to make sure they are written well.
NHS Somerset	**NHS Somerset Integrated Care Board (ICB)** works with health and social care teams to help them to make services better.
	We want to do **more work with people with a learning disability and autistic people** to help make care and support better in Somerset.
	We want to say a big **thank you** to all families and carers who have taken part in our reviews. Sometimes it is really difficult to talk about the death of someone you have cared for.

	**2. The people who died**
	This report is about people who died between **April 2024** and **March 2025.**
35 	We were told about **35** people with a **learning disability** who died.
6 	We were told about **6 autistic** people who died.
15 	We did **15 initial reviews.**
19 	We did **19 focused reviews.**

Age

Young and old people died.

A lot of the people who died were between **56-65 years old**.

Gender

26 of the people who died were men.

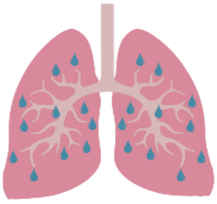
16 of the people who died were **women**.

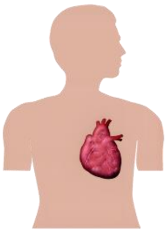
Ethnicity

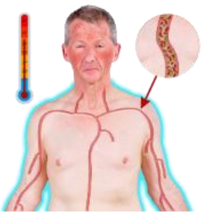
- **40** people were **white British**
- **1** person was **Asian/Asian British**
- **1** person's ethnicity was **unknown**

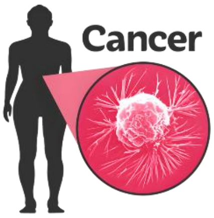
Where people died

- **17** people died in **hospital**
- **13** people died in a **care home**
- **7** people died in their **own/family home**
- **5** people died in **other** places









How people died

Most of the people died of:

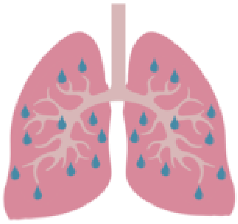
- **Flu and lung infections**
- **Heart problems**
- **Other infections**
- **Cancer**

3. People's Stories

Alison's Story

Alison could not speak or walk and needed a lot of support.

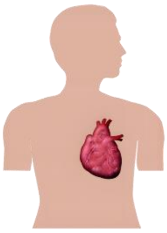
She had lots of health conditions.



It was hard for her to eat and drink safely.

She got lots of chest infections and had to go into hospital.

She had really good support from the Community Learning Disabilities Team to help her to stay healthy.



She died at home after a heart attack.

The ambulance crew were brilliant and very kind.

Arthur’s Story

Arthur had lived in his care home for 44 years.

He loved football.

His carers knew him well and knew how he liked to be supported.

Arthur did not like going to hospital.

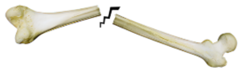
His carers made sure that he could stay in his care home at the end of his life.

Arthur died of old age in his care home.

Fred’s Story

Fred’s last years were very difficult.

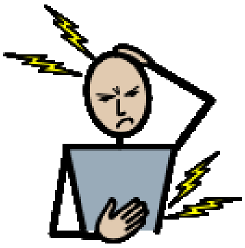
He was diagnosed with dementia.



He had seizures and fractured some of his bones.

He spent a lot of time in hospital.

He should have had medication to help his bones to stay strong.



He got pressure sores and had a contracture of his leg. He was in pain.

He needed earlier help from Physiotherapy.

He died in a nursing home of a chest infection.

Ryan's Story

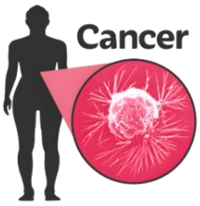
Ryan was autistic.

He lived by himself and did not have any help from carers.

He had a job and lots of friends at work.

He started to get headaches.

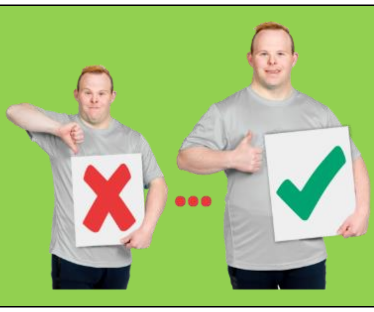
His friends at work helped him to talk to his GP.



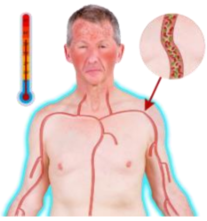
He had tests and found out he had cancer in his brain.

He died in a nursing home.

A Health Passport may have helped people to understand more about his needs.

	**4. What we have done to make care better**
	We have started to think about how to **work more with people with learning disabilities and autistic people** to help us make LeDeR better.
	We did more work to **help people talk about death, dying** and what is important to them.
	We have done work to help people to understand the **Mental Capacity Act**.
	We looked closely into the deaths from **sepsis** in 2023-2024.

	We have worked to find out how many people have a **Treatment Escalation Plan or Advance Care Plan.** These are plans about what people want to happen when they get unwell and near the end of their life.
	We shared information with people about; - **Contractures** - **Oral health** - **Staying safe** - **Menopause** - **Health Passports for autistic people**
	We worked with staff in **GP practices** to help them understand more about people with a learning disability.
	We carried on giving training to people about learning disabilities and autism. This is called **Oliver McGowan Training.**
	We held events to raise awareness in **Learning Disability Week**.

	**5. What we are going to do next**
	**Working together** - We will **work with people with learning disabilities and autistic people** to help us make LeDeR better.
  	**Sepsis** - We will share **information** about sepsis with people with learning disabilities, family and carers. - We will hold a **learning event** about sepsis for people with learning disabilities, families and carers. - We will work to help more people have **vaccinations**.
	**Mental Capacity Act** - We will keep working with health and care staff to help them to understand the **Mental Capacity Act.**
	**Supporting autistic people** - We will **share learning** with the people who fund services about the lack of support for autistic people.

 	- We will work with autistic people and the Somerset Autism Spectrum Service to find out about how **Health Passports** are used by autistic people in Somerset. - We will tell other services about LeDeR reviews for autistic people so that we hear about more people.
	**Epilepsy** - We will share learning with the people who fund services about the lack of support for people with **epilepsy.**
	**Hospitals** - We will work to help people with a learning disability and autistic people have a better experience in the **emergency department.**
	**Annual Health Checks** - We will help to a support a project to make **Annual Health Checks** better.
	**LeDeR Reviews** - We will try to do our reviews more quickly so we can spend more time helping to make services better.

6. Useful information

LeDeR Policy – Easy Read: [LeDeR-Policy-2021-Easy-Read.pdf]

LeDeR Annual Report – Easy Read: [LeDeR 2023 accessible report paper version draft 2]

Somerset End of Life Care and Bereavement Support: [Somerset - End Of Life Care & Bereavement Support]

If you would like to see this report using Makaton signs, click here:

https://nhssomerset.nhs.uk/about-us/equality-diversity-and-inclusion/learning-disabilities-and-autism/

If you would like any more information about this report, please contact the LeDeR team:

Email: somicb.leder@nhs.net

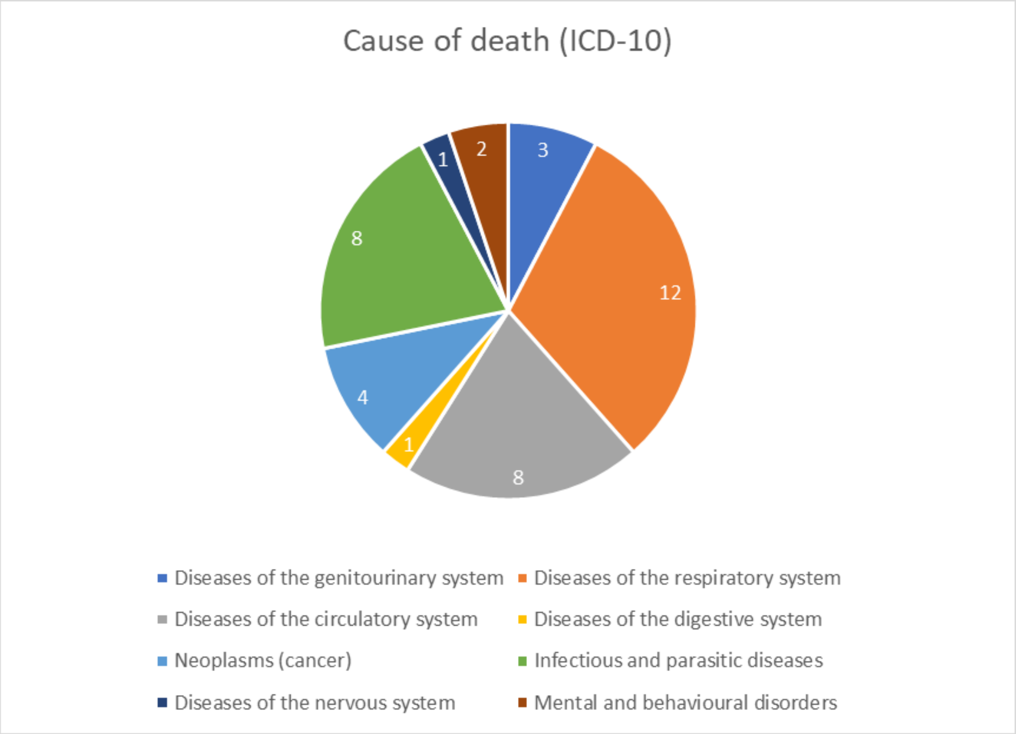
Telephone: 01935 384000

APPENDIX 2

ANNUAL REPORT – SEPSIS DEATHS 2023–2024

Background

The NHS Somerset LeDeR Annual Report 2023/24 found that the joint second most common cause of death for people with LD in Somerset in that reporting period was ‘infectious and parasitic diseases’ (eight deaths). Of note is the fact that five of the deaths in the ‘infectious and parasitic disease’ category related to sepsis. Whilst these five deaths differed in their contributing cause of death, we proposed to carry out a deep dive into these deaths to ensure any thematic learning has been identified and followed up appropriately.



Due to differences in reporting periods and processes it is difficult to make a direct comparison. However data from the most recent LeDeR annual report (White et al 2024) suggests that the following were the most common causes of death of people with learning disabilities in 2023:

- Neoplasms (cancers) 16.6%
- Diseases of the respiratory system (16.5%)
- Diseases of the circulatory system (16.4%)

There does not appear to be specific data relating to sepsis deaths in the national report, suggesting that during that time period, it was not a significant concern.

Literature Review

Sepsis is a life-threatening condition that requires emergency treatment. It is a dangerous complication that can arise from any infection a person may already have. It is the body's reaction to the infection and means the body attacks its own organs and tissues (The UK Sepsis Trust). Anyone can get sepsis, but some people are at an increased risk due to vulnerability and difficulty fighting off infections. People are more at risk if:

- They are very young or very old
- They have long-term health conditions like diabetes or heart disease
- They have had recent surgery
- They take certain medications, like steroids
- They have immune system problems
- They are pregnant / just given birth
- They are severely underweight

The UK Sepsis Trust estimate that rates of sepsis in the UK may be as high as 260,000 cases annually and suggest that 10,000 deaths could be avoided each year.

Without treatment, the body's systemic inflammatory response to infection causes organ damage, septic shock and eventually death. Of the people who receive treatment and survive sepsis, many will experience long-term physical and psychological adverse effects, such as organ dysfunction, chronic pain, fatigue and post-traumatic stress disorder (Grant et al 2021).

Zhong et al (2023) found that factors including deprivation, comorbidity, and learning disabilities were associated with an increased risk of developing non-covid sepsis and 30 day mortality. They found that people with learning disabilities were almost four times as likely to develop sepsis than the general population. They also found that multiple prior courses of antibiotics were associated with an increased risk of developing non-covid sepsis and suggested that this reinforced the importance of targeting antibiotics to patients "who would most need and benefit from them."

UK Sepsis Trust joint chief executive officer Ron Daniels said, "People in vulnerable communities are at greater risk of developing and ultimately succumbing to sepsis. This highlights the urgent need for the NHS to deliver accessible and context sensitive messaging to populations in areas of higher socioeconomic deprivation, to people of non-white ethnicity, and for people with learning disability and their carers."

Kapoor and Singh (2021) found that 'sepsis is attributed to 11% of total mortality among people with learning disabilities who may face challenges in one or more aspects of cognitive information processing including recognising and articulating signs and symptoms of the illness, comprehension of treatment instruction and associated anxiety.'

Doherty et al (2021) wrote that sepsis can be challenging to recognise because there is no one single presenting sign and as it may initially present similarly to conditions such as influenza, gastroenteritis or a chest infection. They raised that it can be challenging to recognise sepsis presentation in people with learning disabilities in a timely manner:

‘As many other conditions, sepsis can be particularly challenging to recognise and diagnose in people with learning disabilities, because they may find it difficult to articulate how they feel and to recognise the need for urgent medical attention. In people with learning disabilities, the experience of pain or of feeling unwell can sometimes manifest as changes in their normal behaviour or as behaviour that challenges. This can lead to diagnostic overshadowing, where all changes in a person are attributed to their learning disability and not acknowledged as the possible manifestation of a physical illness.’

They summarised that improving awareness of sepsis within the learning disability population and providing accessible information to aid understanding, is vital in reducing avoidable deaths among people with learning disabilities.

Heslop and Lauer (2023) carried out a systematic review into strategies to prevent or reduce inequalities in specific avoidable causes of death for adults with learning disabilities. They listed sepsis as one of the 8 most frequently occurring, potentially avoidable causes of death in people with learning disabilities. There were no peer-reviewed journal articles focusing specifically on the prevention of sepsis in people with learning disabilities, however other studies recommended important strategies which could be utilised. These strategies included improving knowledge about sepsis signs and symptoms, uptake of recommended vaccinations (pneumococcal for elderly people and meningococcal for adolescents and young adults), effective handwashing and general hygiene, maintaining mobility, ensuring optimal nutritional status and adequately treating wounds and other infections.

Sepsis Deaths in Somerset (2023-24)

There were five sepsis related deaths notified to the Somerset LeDeR Team in 2023-24. One of these deaths was deemed to be ‘out of scope’ for Somerset and was transferred to another LeDeR Team for review completion. Therefore, the information below is a summary of the four remaining reviews.

Review type

- Two of the people had Initial Reviews.
- Two of the people had Focused Reviews.

Rationale for the two Focused Reviews was as follows:

- A Focused Review is required as the person was from a Romany culture. In addition the cause of death was sepsis due to aspiration pneumonia and an intra-abdominal abscess and a safeguarding referral was initially raised by the acute hospital about the person’s PEG and how it was managed.
- Focused Review required to explore issues around mobility and contractures, antipsychotic medication and care in hospital.

Demographic information

- Two of the people were male and two were female.
- Three people were White/British and one was from a Romany background.

- One of the reviews was for a person with a mild learning disability. One person had a mild learning disability and a diagnosis of autism. One person had a severe learning disability and one person had a profound and multiple learning disability (PMLD).
- Three of the people had significant communication difficulties impacting on their ability to express pain and describe physical symptoms.
- Age of death varied: 40, 46, 76 and 87 years old.

Place of death

- Three of the deaths occurred in an acute hospital setting. One death occurred in the person's nursing home, shortly after discharge on EoL care.

Genetic condition, syndrome or birth related condition

- Two people had a genetic or birth related syndrome/condition: The person with a severe learning disability had Seckel Syndrome and the person with PMLD had Cerebral Palsy.

Long term health conditions

All four people had long term health conditions listed in their medical information:

- Three people had dysphagia. Two of these people had a Percutaneous Endoscopic Gastrostomy (PEG), a tube in the stomach for feeding, hydration and medication.
- Three people had gastro-intestinal (GI) conditions (including constipation).
- Two people had a BMI under 18.5 (significantly underweight).
- Two people were recorded as 'living with severe frailty'.
- Two people had chronic kidney disease.
- Other long term medical conditions recorded were, diabetes, cancer, hypertension, BMI over 30 (obesity), mental health conditions.

Cause of Death (COD)

1(a) Disease or condition leading directly to death:

- Sepsis was listed under '1(a)' on the Medical Certificate of Cause of Death (MCCD) for all four people however the detail of this varied:

    - Sepsis due to aspiration pneumonia and intra-abdominal abscess
    - Biliary Sepsis
    - Sepsis
    - Sepsis of unknown origin

1(b) Other disease or condition leading to 1(a):

Conditions varied for all four people depending on the source of the sepsis:

- Swallowing difficulties and requirement for PEG feeding
- Metastatic Liver Cancer
- Spontaneous Intestinal Obstruction
- None listed

1(c) Other disease or condition, if any, leading to I(b):

- Seckel Syndrome
- None listed
- Gallstone Ileus
- None listed

2 Other significant conditions contributing to death but not related to the disease or condition causing it:

- None listed
- Type 2 Diabetes, Chronic kidney disease
- Urinary Tract Infection
- Chronic kidney disease stage 3

Avoidability of death

Structured Judgement Reviews (SJR) were completed for the three people who died in acute hospital settings. An SJR is a structured review of patient notes/records, carried out by clinicians, to determine whether there were any indications of problems in the care provided to a patient. They are completed for all adults with learning disabilities who die in an acute hospital and include a judgement on the avoidability of the person's death.

All three deaths were recorded as 'definitely not avoidable.' An SJR was not completed for the 87 year old person who died in his nursing home following discharge from hospital on End of Life Care.

Themes

Issues, concerns or potential problems

It is important to note that none of the reviews highlighted issues regarding the identification and/or treatment of sepsis. There were multiple individual issues raised in the reviews relating to other areas of care and support which are summarised below:

- A person lived at a community hospital for five months as no nursing bed was available.
- Issues with discharge summaries and documentation regarding the recording of medications and dosage.
- Chest Management Plan not implemented while in community hospital.

- Health professionals not always aware of difficulties with communication and following instructions.
- Lack of evidence that the Mental Capacity Act was followed to ensure that family were fully involved in all best interest decision making.
- Delay in discharge and poor End of Life (EOL) care.
- Safeguarding concerns regarding the person’s condition on discharge from hospital on EOL care.
- Lack of referral to Specialist LD Service.
- Lack of review under STOMP.
- Delay in identification and referral for management of contractures.

Positive Practice

Positive practice also varied across the four reviews:

- Good involvement from Somerset acute hospital clinicians from different specialisms in providing support and medical expertise.
- Evidence of care provider contacting GP promptly to report changes and for advice.
- GP practice very responsive to care setting and dealt with issues promptly.
- Family expressed their appreciation of the care received at the community hospital.
- Complex care doctor assisting with easy read options and modified language to understand what DNACPR meant to complete this paperwork.
- Easy read dietetic care plan produced with pictures by mainstream dietetic service.
- Professional curiosity and LD awareness displayed by junior doctor.
- Good communication and reasonable adjustments by GP practice.
- Significant multi-agency engagement towards the end of the person's life, enabling a more joined up approach to care and support.

Learning into Action

- Raising awareness - We will liaise with our Infection Control colleagues to create and share information with people with learning disabilities and their carers in Somerset about sepsis and the signs and symptoms. Information should highlight common factors and vulnerabilities evidenced from the reviews above, from a review of current evidence e.g. dysphagia, frailty, gastrointestinal conditions, communication difficulties.

- Alongside communications about sepsis, the LeDeR team will hold an accessible Lunchtime Learning session on sepsis with support from the Infection Control team. This will be available to our network of LD Champions but attendance can also be widened and offered to people with learning disabilities and their carers via the local carers’ network.

- We will work with our vaccination team to increase the uptake of pneumococcal vaccines in high-risk groups within the learning disability population.

- We will continue to promote the use of patient deterioration tools and signpost to these in our communications and learning session.

References

Doherty P, Barksby J, McCorkindale M (2021) Signs and symptoms of sepsis: raising awareness in the learning disability community. Learning Disability Practice. Volume 24, number 2.

Grant N, Hewitt O, Ash K, et al. (2021) The experiences of sepsis in people with a learning disability – a qualitative investigation. British Journal of learning Disabilities.2022;50:514-524.

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Resources

NHS England: Easy read information: Sepsis
www.england.nhs.uk/publication/easy-read-information-sepsis
Easy read information about how to avoid sepsis, spotting the signs of sepsis, and problems after sepsis.

Health Education England (HEE) – Resources on sepsis
www.youtube.com/watch?v=LIZk9A6bBWw
A film giving more details on a series of training films about sepsis and managing deterioration for clinical staff and others including those in paediatric settings.
www.e-lfh.org.uk/programmes/sepsis/ - ‘THINK SEPSIS’ is a HEE programme aimed at improving the diagnosis and management of those with sepsis.

www.hee.nhs.uk/our-work/sepsis-awareness - More details on sepsis awareness in primary care to senior staff.

Sepsis Trust
https://sepsistrust.org/professional-resources/education-resources
Short films and guidance for professionals about sepsis and how to identify it – includes a sepsis manual and educational videos.

East and North Hertfordshire NHS Trust and Hertfordshire County Council
www.hertfordshire.gov.uk/media-library/documents/adult-social-services/learning-difficulties-and-dementia/sepsis/what-is-sepsis-easy-read.pdf
Easy read signs of sepsis information leaflet from East and North Hertfordshire NHS Trust.

Purple All Stars – Check me for sepsis
www.youtube.com/watch?v=FZq5sYulOB8
Purple All Stars (a creative arts group of people with a learning disability) has produced a song and video about sepsis which aims to educate people with a learning disability and the people who support them, to know what sepsis is and when someone has possible signs to remember to ask the health professionals, ‘Is it sepsis?’

APPENDIX 3

‘My Brother John’

I recently lost my brother John at the age of 78. His death was quite unexpected so it came as a complete shock to me and the members of our family and indeed to all who knew him. You see John was a very special person.

John was born in 1946 in Somerset. I was only 1 year and 9 months old at the time so I have no memory of the occasion but from what I have been told it was a normal birth with no complications. All went well at the start of his life but gradually my mother began to notice that his development appeared to be much slower than mine had been. When she sought advice on this, her fears were completely dismissed out of hand, she was regarded as just another overanxious mother. She was, however, not wrong. John's development was slow and eventually it was recognised that he was 'handicapped' as the terminology was in those days. It was thought that perhaps the reason was lack of oxygen at birth but I don't think there was ever a formal diagnosis.

I was too young at the time to acknowledge how my parents felt, when faced with their situation, but supported by my paternal grandparents, who were wonderful people, they did the best they could to carry on. My Dad was, however, advised by a male member of my mother's family, that the best thing for all concerned was to 'put John away' then they could have a more 'normal' life. My dad was horrified at this suggestion and, together with my mother and his wonderful parents, became determined to do the very best they could to help John progress.

At this time, facilities for 'the handicapped' were poor. The war had only recently come to an end, there was a housing shortage, food was still rationed and the National Health Service didn't begin until 5h July 1948. The odds were definitely stacked against them and often parents, at that time, were advised by doctors to 'put him away and forget all about him' or 'put her away and have another child'.

The birth of such children was seen, in those days, even by the medical profession, as a tragedy or misfortune. To 'put him/her away' meant into a long-stay mental institution but sometimes parents who were put in this position felt obliged to do so as there was little or no other help or support on offer. I've visited a couple of such institutions back in the 1970's and, even then, the less said about them the better.

My parents, supported by my wonderful paternal grandparents, thought otherwise I am pleased to say, so John remained within our family unit and I think his presence probably made us all more thoughtful and indeed better people.

John's initial progress was slow and he looked very weak but my wonderful grandmother suggested to my parents that she and my granddad would like to be involved in caring for him (and me when I came home from school each day) and that my mother might like to get a job as Nan felt she might benefit from the mental stimulation. Nan and Granddad only lived in the next road and we were a very close integral family. When John reached the age of five, my parents were informed that he was ‘ineducable’.

‘Mentally handicapped’ people were not seen as being part of society in those days and now, with hindsight, that makes me feel very angry and thoroughly ashamed of peoples' attitudes.

Through our lack of knowledge, it seemed that there was nowhere for John to go during the day for any form of stimulation so he stayed with Nan and she became his 'teacher'. She was such a wonderful, selfless individual and taught John so much including how to write his letters and how to tell the time. Shortly after his fifth birthday John became very ill and it looked almost certainly that he would die. I remember, clearly, seeing my granddad cry that day because they were so fond of him and that really upset me. However, John turned a corner and survived and never seemed to look back after that worrying episode.

Eventually, but only through word of mouth from a neighbour, my parents learned that there was a group for 'mentally handicapped persons' running in a local hall in the town centre and made enquiries for John to attend, which he then did on two days a week. This was run by Somerset County Council's, health department, who incidentally my mother was working for, but why they had never been informed of this officially we will never know. I suspect it was the left hand not knowing what the right hand was doing!!! The attendees were all ages, however, not just school age but those with a mental handicap were regarded and treated like children at that period in time anyway. It was known as an Occupation Centre' where the attendees were simply offered occupation. The centre was very basic and run by two ladies but it was, at least, something. In time John increased his attendance to five days just as he would have done had he been 'normal' and attending school.

As time moved on the occupation centres became known as training centres and those over the age of nineteen attended adult training centres leaving the school age children in a junior training centre.

In 1970 the Education (Handicapped Children) Act was passed and the junior training centres finally became the responsibility of the local authority education departments when all children were entitled to an education so these centres became special schools. It was also in 1970 that Social Services was formally structured and they took over the responsibility of the adult training centres. By this time John was twenty-three so he had completely missed out on any formal education. Although John was denied an education, he had developed many, many interests. He loved buses from a very early age, he loved music both pop and classical, he was fascinated by clocks and had his own wrist watch and later developed a keen interest in ferries. He also loved watching television. The family very much encouraged his interests. He had a pocket radio so he could listen to music whenever he liked, he had his own small television in his bedroom, and he had his own tape recorder on which he was an expert at finding set pieces of music. He also had a swing in our grandparents' garden which we both enjoyed, I like to believe John enjoyed his life.

We were just like any other family. We enjoyed family holidays, celebrations, outings, time with friends etc but in addition we tended to put John's interests first so that he could enjoy special time. This included visits with Nan to her sisters, one in Essex the other on the isle of Wight which also meant a ferry crossing which he loved. Once I was married, John frequently came to stay with me in Hampshire.

John also loved special occasions like Christmas and the traditional way we gave out our presents; Easter and the Easter egg hunt when we followed all the rhymes that Dad had written; North Petherton carnival with friends who visited all the way from Cumbria and Gloucestershire and of course his birthday with endless presents, a birthday cake with candles and singing Happy Birthday dear John.

As time went by of course things changed. First of all, we lost our granddad in 1964 just after I married Neil. John seemed to take that loss quite well. In 1965 my parents moved from Bridgwater to North Newton, a village some five miles away, and Nan moved from her large house in the next road, into our smaller one. The arrival of my two daughters Mandy in 1965 and Tracy 1970 John accepted well although he didn't like them crying when they were babies. Then we sadly lost Nan in 1973, this did affect John a little as they had a very, very close relationship. It also posed a major problem as Mum wasn't due to retire until 1977. John travelled by mini bus into Bridgwater each day to attend the centre which by now had been re-built and upgraded to an excellent one named The Enterprise Centre. and those who were diagnosed as 'mentally handicapped were now known as having a learning disability' Unfortunately, the centre closed each day at 4 pm, and with no Nan to receive John when he arrived home a problem arose. Mum thought she may have to retire early but then her next door neighbour kindly offered to take care of John each day and provide him tea and biscuits until Mum or Dad arrived home a little later!

For the next eighteen years life went along quite smoothly but then my parents decided that they really ought to think about the future for John as it was quite possible that he would outlive them.

They searched for some time for a suitable residential home but found this undertaking to be a dreadful task. When they finally found Cliffe View House in Cheddar, run by Somerset County Council, they felt happy with what they observed. John moved there in 1991 at the age of 45 but only part time, which seemed very appropriate, he went home every weekend for several years and longer spells at Christmas, Easter and other holidays.

Finally, he became a full-time resident just going home to my parents once a month when Neil and I visited too. This wasn't what my parents wanted but they realised it had to be. They knew as they became older looking after John would become more difficult for them so they were just being realistic.

Sadly, my mother started to decline mentally around 1998 and died in 2002 aged 84. Dad was physically disabled but remained extremely mentally alert and continued to live on his own until 2006.

Neil and I visited him every month for the weekend accompanied by John. Once I retired in 2004 John also visited Neil and me for holidays enjoying trips on his beloved open-top buses and visits to the Isle of Wight travelling on his well-loved ferries. He also enjoyed visiting some of my friends who always made him very welcome and provided him with lunch or afternoon tea.

Dad had several bouts of ill health and finally decided to go into residential care in 2006 but we continued to visit him once a month at the care home, together with John, until he died in 2009 just seven weeks before his 91* birthday.

Surprisingly John appeared to take the death of our parents well but obviously I'll never know how he really felt as he never expressed sadness.

John's life took a slight change at this juncture. Instead of us visiting Dad, Neil and I visited John in Cheddar every month and took him out to lunch then usually a run in the car to Burnham on Sea. We also had him to stay with us for two-week holidays, four times a year, namely Christmas, Easter, summer holiday and his birthday in September.

Sadly I lost Neil in September 2023. John found this difficult and would often ask me what Neil was doing. Nevertheless, Tracy and I continued to have John for holidays and to take him out on monthly visits. We were expecting him to be with us for the Christmas holiday when we received the shocking news that he had died on 14th December 2024. When a disabled person enters a family, it obviously comes as a complete shock. Some people can cope well others just can't cope at all. It depends entirely on the individuals concerned. I can honestly say that John had a great deal of influence on many of our family members including me.

My parents both belonged to the local Mencap committee and gave it much of their time. This had the advantage of meeting other parents with disabled offspring. I was also a committee member of my local Mencap committee in the New Forest enabling me to do likewise. Mum and I both worked for Social Services. I trained to work with people with a learning disability.

As I mentioned previously John never expressed sadness but he did express joy. There are so many things John liked to do and we did our best to encourage this. One of his favourite memories was a present from the Wightlink Ferry Company in 2010 after I had written to them expressing his love of ferries. We were then invited to travel with Captain Wendy Maughan on the bridge of the Wight Sky ferry from Lymington to the Isle of Wight and back again including a short stay at Varmouth. I cannot put into words the joy and excitement John experienced from that special day and he continued to talk about it for ever more. He had an album of photographs for memories of the day that Neil made for him which was never far away and he also had a framed photograph in his bedroom at Cliffe View, and at my house, of Wendy, John and me taken on the bridge of the Wight Sky.

I will be forever grateful to the Wightlink Ferry company for their generosity and kindness. They will never know how happy they made John for that wonderful experience of a lifetime.

I will never really know if John was happy in his life but I like to believe he was. He would never dwell on 'bad' things, if he had not been well and you asked him how he was he would always answer "I'm better now" he never seemed or wanted to be unhappy.

Perhaps that's a lesson to us all!

John's life in the 1940's may have been regarded as a misfortune or a tragedy but I can only see the positives that have come about as a result. I had a very successful career which was only as a result of having John as my brother. I have made many lovely friends through my work. I even experienced a visit to Buckingham Palace and MENCAP headquarters where I had lunch with Brian Rix, all as a result of working with people with learning disabilities.

Had my dad taken notice of the relative who told him to 'put John away' our lives would have missed out on so much.

In our family ‘misfortune’ developed into ‘good fortune’. What’s more I am delighted and very proud to say that both my grandchildren have found careers working with disabled people. My parents and grandparents would have been so proud and it’s all because of my brother John.