Learning from Lives and Deaths – People with a Learning Disability and Autistic People

(LeDeR)

Norfolk and Waveney

Annual Report 2023-2024

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Forewords

Patricia D’Orsi: Executive Director of Nursing for the Norfolk and Waveney Integrated Care Board (NWICB) - Senior Responsible Officer (SRO) for the Learning Disability and Autism (LD&A) Programme Board

On behalf of NHS Norfolk and Waveney Integrated Care Board (ICB), I would like to welcome the publication of our seventh LeDeR Annual Report in Norfolk and Waveney and recognise the breadth and depth of its analysis and learning. I would like to recognise the local LeDeR Team for the skill and empathy required to undertake this work to such a high standard.

The ICB continues to be grateful for the contributions made by families, carers, and friends. The importance of ensuring that each review reflects the person at the centre of it; their character, interests and what they meant to those who knew them, is particularly powerful in the report’s section on lived experiences, which can be found on pages 50-59.

I would also like to recognise and thank staff from across the health and social care system for sharing the records and information required to complete each review to a robust and high standard, as well as the insights shared from their professional practice and from their time spent with the people and families whose experiences are central to this report. The organisations that provide health and social care are also key in taking forward learning into action and support for the programme continues to be outstanding.

Sadly, people living with learning disabilities and/or autistic people continue to have a much shorter life expectancy than the wider population and are more likely to face health inequalities that lead to poorer care access, experience, and outcomes, which can impact significantly on physical and mental health and wellbeing.

The data presented in this report shows that the leading single cause of death in Norfolk and Waveney over the past twelve months for people living with learning disabilities and/or autistic people continued to be aspiration pneumonia and other respiratory conditions. Therefore, the focus on respiratory health and prevention continues to be a health improvement priority for us; building on the work of the previous year. It is positive to note that COVID-19 and Flu vaccination uptake is performing well and that we have plans to further improve access to the pneumonia vaccine.

Diagnosis and treatment of cancer was also a significant theme within the deaths reported, as the third single cause of death. This has informed work targeted work around early diagnosis of bladder cancer, including a review of referral pathways and a plan for a programme of clinical training. Wider work around addressing barriers for cervical and breast screening also continues and we must work towards better equity of access to interventions that helps catch cancers early and improve outcomes and survival rates.

I would like to acknowledge the work undertaken to standardise and improve uptake of the NHS Annual Health Check (AHC) and Health Action Plan (HAP). Practices have been able to work with the ICB Health Improvement Team to access support around improving the quality and accuracy of their patient data, developing skills and confidence, and understanding and implementing reasonable adjustments. The focus for the year ahead is to share good practice and improve how AHC and HAP are used as meaningfully as possible.

Palliative and End of Life Care also continues to be a core part of the programme and there is evidence of improved practice around DNACPR decision making, which demonstrates better planning and support around those ‘big decisions’ at the end of a person’s life.

Finally, I would like to highlight the LeDeR Team’s work this year within education and training. Collaborative work with University of East Anglia has generated excellent student feedback on sessions and resources that will help develop learning disability and autism education within health and social care courses, to help raise awareness and shape practice for our future workforce.

The ICB continues to be committed to ensuring that people living with learning disabilities and/or autistic people live well, and we recognise that the development of services and care pathways must be informed by people’s lived experiences. I support the improvement priorities identified across the year ahead and look forward to working with the LeDeR Team to take this work forward over the year ahead, to further improve the lives of people living in Norfolk and Waveney.

Rachel Clarke: Co-ordinator for Family Voice Norfolk
My name is Rachel Clarke and I am proud to have been asked to contribute to this foreword for the second year running. I am the co-ordinator of Family Voice Norfolk (FVN), the Norfolk parent carer forum for families who have children and young people with special educational needs and/or disability aged 0-25 years. We are not a support group, nor are we an advisory and guidance service. We are a forum which gathers real-lived experiences and views of families to work in co-production to improve services within health, education, and social care.

FVN has been attending the LeDeR working groups, the Learning into Action Group, and the LeDeR Steering Group for over two years. We currently have two parent carer representatives attending these meetings, namely Laura Godfrey and myself. Both

Laura and I are parents of children and young people who have autism, learning disabilities and other conditions. Laura's son is moving into the realms of preparing for adult life where support and planning are key. My own son is in his twenties and although fully supported at home, and within adult services, we work every day towards him being able to be more independent in his way. Independence looks very different for each of our unique children and young people.

We believe that having parent carers present at the LeDeR meetings brings a different dynamic and different perspectives at times. We are able to put ourselves in the shoes of families involved and, hard as it may sometimes feel, think about the future care for adults who are autistic and/or have a learning disability, whether they be independent in their community or within a supported/residential setting. What would we expect to see from care for these adults? What would we want to see done differently in the care of adults as our young people will become adults themselves? There have been some extremely 'difficult to read' and, rightly so, emotive cases to review. Over the past year, we have been struck, at times, how young people have become 'lost' when no longer in education and less likely to be on any service's radar for support. This is something that needs addressing. It is exactly those cases where things have been 'missed', no matter at what age or stage of a person, that make the learning from the LeDeR work so vital.

As parents and carers, we want to be able to trust that, when we are no longer around for our sons and daughters, the best is done for them within the best environments. Each time we review an individual, we reflect on the importance of the annual Learning Disability Annual Health Check throughout a person's life, how crucial this can be in the early identification of emerging health problems and how important these checks are in ensuring a person is known by their primary care practice. We know there are inconsistencies in the quality of how learning disability annual health checks are conducted and we understand that there is ongoing work and training around this. Through LeDeR and the Learning into Action Group meetings we attend, we have heard about the learning from tragic deaths within residential homes and how important good housing and the support within it, is. As parents, it gives us much to think about for our young people and their adult lives.

Laura and I understand how dedicated everyone is within the meetings to make improvements, prevent recurrences of failings and to truly take learning from each case we review. We are grateful for the support and 'open ears' that are offered to us by colleagues should we find a case to be upsetting. There are times when the cases do make us think 'this person is exactly like my own'. The drive to learn from the deaths of people who are autistic or have learning disability, is tangible. There are sometimes examples of good or exceptional care. These are heartening to hear and again, learning is taken from these as examples of good and best practice. On behalf of Family Voice Norfolk, I should like to say how pleased we are to be part of the groups and the work going forward.

Contents

1. Acknowledgments

Firstly, the team would again like to remember, and thank, all the people who have contributed to LeDeR by sharing their stories with us, following their death. It remains our greatest privilege to be given the opportunity to explore their experiences, and our primary aim is always to use all information in a compassionate and respectful way. Thanks also again go to the families, friends, and keyworkers of those we are reviewing, who contributed their time to enrich the information we had and help us find their voice.

Secondly, the LeDeR programme would not have been possible over that last year without the care, expertise and time given by health, social care, and voluntary sector colleagues. Delivering real and sustainable change takes a commitment of resource, and this has been freely given and gratefully received. Colleagues have supported the LeDeR groups and our learning into action project work. Special thanks go to our partners with lived experience for their guidance, support and challenge.

LeDeR reviews are not an investigation of a death but an assessment of a person’s experience. This aims to bring to life the circumstances leading up to the person’s death and provide a life portrait of the people we have reviewed. This can be a difficult and challenging role but has been fulfilled by a team of highly experienced and dedicated nurses and administrators, who have been central to delivering the programme.

We would also like to acknowledge with much appreciation the crucial role of the health and social care staff, who have diligently delivered high quality care to people with learning disabilities and/or autistic people over the last year.

2. Executive Summary

Welcome to the Norfolk and Waveney Integrated Care Board (NWICB) LeDeR report. This is the seventh annual report in Norfolk and Waveney on the reviews of the lives and deaths of people with a learning disability and/or autism since the inception of the LeDeR programme in England in 2017. It is the responsibility of all Integrated Care Boards (ICB) to have established a LeDeR programme within their system and implement any actions identified by the learning taken from reviews.

ICBs must publish a LeDeR annual report describing their progress in completing reviews, provide interpretations of the collected data and detail completed and ongoing service improvements made in response to any learning. It also provides an opportunity to reassess local priorities in response to any themes or trends. This report from the Norfolk and Waveney LeDeR programme demonstrates the work covered in the reporting period from 1st April 2023 to 31st March 2024. The deaths reviewed can cover a longer period dating back to early 2022. This is due to death reporting delays but also delays in the review completion.

There will be some comparison available between this and last years' annual report due to significantly more robust local data collection. Comparison will be limited between this year and last year, so extrapolations are of course limited. As such, analysis primarily describes the current situation in Norfolk and Waveney and continued work over the coming years will be able to better highlight trends and improvements.

Comparisons can be made between Norfolk and Waveney and the regional and national picture by reading this report alongside the East of England and National Reports[1]. Summary findings from the Norfolk and Waveney reviews in 2023/2024 can be seen on the next page:

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[1] https://www.kcl.ac.uk/news/2022-leder-report-into-the-avoidable-deaths-of-people-with-learning-disabilities

More people have had their pneumonia, flu and COVID vaccinations than last year.

As a region we achieved 74% completion of annual health checks for those eligible, an increase on last year.

Use of ReSPECT forms has increased, but work is needed to solidify good use as an emergency care planning tool.

Evidence of good quality DNACPR decision making has increased from 66% to 93%.

The median age of death in last years reviews has increased from 57.5 years old to 62 years old.

58% of deaths were coded as avoidable, which is an increase from last year. However, we believe this is due to better MCCD completion.

Acute and community learning disability nurses are key supports for improving service access and reasonable adjustments.

Primary care are good at offering face to face appointments and we have seen improved preparation for interventions such as blood tests.

Notifications for those with autism have increased but there is room for further improvement.

Focused review gradings have demonstrated improvements in assesed quality of care and access to services.

Epilepsy and hypertension continue to be the two single leading comorbidities seen in reviews.

For the first time since 2020, we had no reviews with COVID-19 as a cause of death.

More people had bowel cancer screening last year, but uptake of breast and cervical cancer screening remains low.

Respiratory disease remains the leading cause of death, with pneumonia still the most frequent cause of death.

Overall we have had 29% more notifcations this year. This is due to increased awareness of LeDeR across the system.

Of the people we reviewed, 43% died over the age of 65 years old. This is an increase from 21% last year.

Most people had a healthy BMI, but we did have more people recorded with a BMI in the obese range of <30.

Reviews this year have shown evidence of a decrease in adherence to MCA and DoLS.

Reviews this year demonstrated less people were prescribed psychotropic medications, especially for behaviour.

Prevention of respiratory illness is a priority for the whole system, including dysphagia management, dental care and vaccination.

3. Introduction and Purpose (Local and National)

3.1 What is LeDeR?

The LeDeR programme reports on deaths of people with a learning disability and/or autism aged eighteen years and over. Latest figures available estimate there are approximately 1.2 million people (951,000 adults and 299,000 children) living in England, known to have a learning disability[2]. As at the end of March 2024, 6,868 people were registered with GP practices as having learning disability in Norfolk and Waveney, out of a total population estimate of 1,032,472[3]. Our area has one of the highest percentage learning disability representations in England[4].

People with a learning disability are considerably more likely to be impacted by health inequalities, including higher levels of avoidable and premature deaths. For example, the latest data from the 2022 National LeDeR Report demonstrates the disparity in age of death for those with a learning disability. Compared with the general population, males with a learning disability die 20 years younger and females die 23 years younger[5]. This inequity is something we wish to address within Norfolk and Waveney, through a continuing programme of change informed by learning from LeDeR.

The LeDeR programme[6] uses the national policy's definition of a learning disability. For autistic people to be included within the LeDeR programme they must have a diagnosis of autism recorded within their health records prior to their death. The child death review (CDR) process reviews the deaths of all children aged under 18 years. This is the primary review process for children with learning disabilities and autism, which is completed collaboratively with the LeDeR programme. A full explanation of the review process including national priorities for a focused review can be found in the LeDeR policy[7].

When reading the findings of this report it should be kept in mind that the LeDeR programme is not mandatory so may not have complete coverage of all deaths of people with a learning disability and/or autism. Comparatively, numbers are also small compared to the general population, and as such must be interpreted with caution. Data interpretation and analysis is an important

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[2] https://www.norfolkinsight.org.uk/wp-content/uploads/2022/03/Briefing_paper_Disability_Adults_with_Learning_Disabilities_May_2018_accessible.pdf
[3] https://www.norfolkinsight.org.uk/
[4] Quality Assessment Framework 2021/2022
[5] https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf
[6] https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf
[7] Section 3/page 12 of https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf

part of finding trends in poor practice and identifying gaps where improvement is needed. However, we also aim to present person focused qualitative learning which represents people's strengths, talents, hopes and ambitions.

3.2 Reporting a Death

Anyone can notify the programme of a death or person with learning disabilities and/or autism at https://leder.nhs.uk/report

3.3 Local Programme

Within Norfolk and Waveney, we are committed to improving services for people with learning disabilities and/or autistic people and use the framework set out in the LeDeR policy by NHS England. Data collection significantly changed for 2022/2023 and this allowed us to provide a more detailed report last year, and subsequently this year.

4. Challenges and changes to delivery of the LeDeR review programme

The success of the LeDeR programme is built on the efforts and input of the LeDeR team and the wider contribution from Integrated Care System (ICS) partners and colleagues. The team has continued to strengthen their quality of work, supported by local governance, robust escalation routes, a systemic approach to learning and creating education routes to update the wider health and social care community on learning from LeDeR. We have experienced many challenges in delivering LeDeR over the past year, capacity has been reduced in the team, while the number of notifications and number of focused reviews have both increased. This has resulted in a drop in performance.

All reviewers are reliant on the timely provision of notes from all involved services to complete a review within the 6-month target. This includes notes from acute trusts, primary care, community trusts and social care. Mostly the team will receive at least one set of notes back within 2 weeks of the request being sent. However, responses to all requests can take up to several months which significantly delays allocation and completion of reviews. Reviewers also rely heavily on talking to carers and professionals who knew the person well to get a complete picture of the person they are writing about. Care providers can sometimes be difficult to engage in this process which restricts the information available to really tell a person's story and describe their lived experience.

Due to improvements in the timeliness of reviews families are being contacted and invited to particate in the LeDeR process much sooner after the death of their loved one and we believe due to this, we are seeing more families choosing not to be part of the review. We have delayed completing reviews at the request of the family to give them more time, even if this takes the review over 6 months, as we recognise the importance of a loved one's contribution. We will also still offer families the option of receiving a copy of the completed review should they wish. Where we have a telephone number for a family member, we have implemented a follow up phone call to every invitation letter, to try every method we have, to engage a family. However, this has not been in place long enough to gauge if it has helped.

5. Governance Arrangements

In line with the national policy, we have governance arrangements to support reviewing and signing off completed reviews. As well as clear reporting routes into the Learning Disability and Autism Programme Board and Learning from Death Forum.

5.1 Initial reviews

Initial reviews are presented at the Local Quality Assurance Panel (LQAP) which is chaired by one of the Local Area Contacts (LAC) or another suitably senior person within the Learning Disability and Autism Team within the NWICB. The panel will scrutinise the review for quality and ascertain if the recommendations address the identified learning. Initial reviews are signed off and themes and trends are presented through LeDeR's reporting programme.

5.2 Focused Reviews

Focused reviews go through the same quality assurance and scrutiny process above but are then presented at the Learning into Action Group (LIAG) for sign off which is chaired by either the NWICB LAC or the NWICB Senior Reviewer. This group is attended by key operational stakeholders who will agree the SMART recommendations, care grading, and identify any good practice of note.

5.3 Reporting Structures

LeDeR's reporting structures ensures key themes and learning are shared with senior colleagues and a wide range of stakeholders on a regular basis. This helps us review identified learning, strategic actions, and quality improvement work streams. Reports are presented to the:

- ICS Learning from Death Forum – Every 2 months.
- ICB Learning Disability and Autism Programme Board – Every 2 months.
- ICB Quality and Performance Committee – Every 2 months.
- Norfolk Safeguarding Adults Board – Every 6 months.
- Social Care Quality Improvement Programme – Every 6 months.

6. Performance

The team works to achieve 95% of reviews completed within 6 months of notification. At the end of Quarter 4 (Q4) the team has completed 77% (43 out of 56 reviews) within 6 months of notification in the 2023/2024 year.

Some reviews may take over the 6 months to enable any statutory process to be completed such as police investigations, coroner proceedings or safeguarding inquiries. It is important that LeDeR pauses and gives precedence to these to avoid prejudicing any investigations. We can put these reviews on hold, which in effect “stops the clock” so the delay doesn’t count towards the 6-month timeframe. Reviews which are considered to have exceeded the 6-month timescale included those delayed for reasons such as clinical notes not being received, capacity issues within the review team and giving families time who may not be ready to engage but want to be part of their loved one’s review.

The team have completed 56 reviews this year. Last year the ICB signed off 72 reviews. Last year we completed 7 paediatric reviews, however reviews for children and young people are no longer in scope for LeDeR nationally. To ensure our team still delivers the same contribution to this process, the ICB’s Child Death Review process has been strengthened through collaborative working. Lastly, in 2022/2023, 13 reviews were completed by an externally commissioned provider to clear our historical reviews. So, the ICB team alone has completed more reviews (*n*=56) than last year (*n*=52).

We carried forward 32 reviews from the 2023/2024 review period and this year we are carrying over 51 reviews into 2024/2025, so 60% more than last year. The team is also tasked by NHS England to convert a minimum of 35% of reviews from initial to focused. This year the team has again exceeded this target and achieved 45% of reviews being focused, a higher percentage than last year.

7. Overview of Notifications

As Figure 1 shows how the number of notifications to LeDeR has changed over the years. It is important to note that as reporting to LeDeR is not mandatory, the true number of deaths is likely to be higher. Our team have received 81 notifications in the 2023/2024 period. The team did have an additional notification for child, but as LeDeR no longer reviews those under 18 years of age, this notification has not been included in any analysis as a review did not take place. To compare the number of notifications, 2019/2020 is used due to the number of excess deaths from COVID which is also exampled in Figure 1. Overall, our notifications have increased by 62% since pre-COVID levels with an increase of 29% on last year alone. We believe this increase reflects a higher number of autism only notifications, as well as our continuing work to raise the awareness of LeDeR in our system. We have also seen more robust reporting processes within the coroner’s court, medical examiners and mental health trusts which has meant we received notifications which previously would have been missed.

7.1 Age

The youngest reported death during 2023/2024 was 18 years of age and the oldest was 91 years. Most of our referrals were for people 65 years and over, which is an increase from last year. Overall, the representation across the age groups for men and women was very similar. This year's data shows an increase in the median age at death of notifications from 57.5 years to 63 years of age. Using the latest data from 2018 - 2020, the average age of death for the general population in Norfolk and Waveney is 79 years old for men and 84 years old for women.[8] See Figure 2.

7.2 Gender

Relatively, we had the same number of referrals for men than women, whereas last year we had more notifications for men. See Figure 3.

7.3 Diagnosis

The majority of our referrals were for those with a diagnosis of a learning disability. A small number had a diagnosis of both a learning disability and autism, however this is likely an error in referrals and post review we would expect a higher percentage to also have an autism diagnosis. The team received 6 notifications for people with a sole autism diagnosis, compared to last year when we didn't receive any. It is thought that 1% of the population has autism which would mean approximately 10,330 people in Norfolk and Waveney. The latest standardised mortality rate for autistic people is 17 deaths per 10,000. This shows the LeDeR team what is still being missed and the continued need for communicating the importance of autism referrals will be an ongoing priority for 2023/2024. The medical examiner role for acute and community should go live this year which will aid these referrals, as well work done by Norfolk and Suffolk Foundation Trust (NSFT) who have built in notification of eligible deaths to LeDeR into their new mortality oversight processes.

7.4 Place of Death

Place of death is not a mandatory question for referral completion. At the time of writing, 7 of the notifications did not have an identifiable place of death in the referral or in the available notes. This means some of the figures could change if all information was available. However, from the information we have, most deaths referred to us in 2023/2024 happened in hospital, 52% (*n*=42) overall, and 21% (*n*=17) occurred in the person's usual residence. This means a lower percentage of people died in hospital than

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[8] https://www.norfolkinsight.org.uk/wp-content/uploads/2022/08/State-of-Norfolk-and-Waveney-health-report-2022_correctedByPAVE.pdf

last year, but so did a lower percentage die in their usual residence. The percentage of people dying in hospital is coming more in line with the general population figure of 51%[9]. See Figure 4.

7.5 Month of Death

Looking at the deaths which occurred during the reporting period Figure 5 shows how many deaths occurred by month for the notifications this year and for last year. We have excluded notifications for this year, where the death falls outside of the reporting period. For this year's notifications, 10 deaths happened before the reporting period: 3 in early 2023, 6 in 2022 and 1 in 2021.

7.6 Ethnicity

Of the notifications from 2023/2024 where the ethnicity was disclosed, 100% (*n*=81) were for white British people. The last figures we have for Norfolk and Waveney suggest 5.1% of the general population is from an ethnicity other than white British.

7.7 Leading Cause of Death

From notifications the leading single cause of death (COD) in Norfolk and Waveney was aspiration pneumonia, with all respiratory conditions including chest infections and type two respiratory failure leading across the board. This is the same as last year's notification data and is also seen in the completed reviews from this year. This profile is different to the general population where the top three COD in 2022, (the last available full year of data) for England and Wales, were Dementia and Alzheimer's Disease, followed by Ischaemic Heart Disease, then Chronic Lower Respiratory Diseases[10]. Again, a COD is not a mandatory question for referral completion. As such, at the time of writing, only 45 of the notifications had an identifiable COD in the referral or in the available notes. As such some of the figures may change if all COD were available.

7.8 Area of Deprivation

The Indices of Multiple Deprivation (IMD) again shows a mode score of 6 this year, which is the same as our completed reviews. The overall breakdown in representation into the higher and lower IMD areas is also very reflective of the completed reviews for 2023/2024, with more people with a learning disability and/or autism living in areas with an IMD score of 5 or less. This is still higher

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[9] https://fingertips.phe.org.uk/profile/end-of-life/data#page/1/gid/1938132883/pat/15/ati/221/are/nE54000022/iid/93474/age/1/sex/4/cat/-1/ctp/-1/yrr/1/cid/4/tbm/1/page-options/car-do-0

[10] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2022

than the general population where 2019 data shows 52% in Norfolk live in an area with an IMD score of 5 or less[11]. However, we have seen a narrowing from 34% to 16%, in the difference between the top and bottom 50%.

IMD Score	Number of Notifications	Percentage	Number of Notifications	Percentage
1	8	10%	47	58%
2	6	7%		
3	5	6%		
4	11	14%		
5	17	21%		
6	19	23%	34	42%
7	6	7%		
8	6	7%		
9	2	2%		
10	1	1%		

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[11] https://www.norfolkinsight.org.uk/deprivation/reports/#/view-report/8b97d75c317745b3a6016fc0788469d1/E10000020/G3

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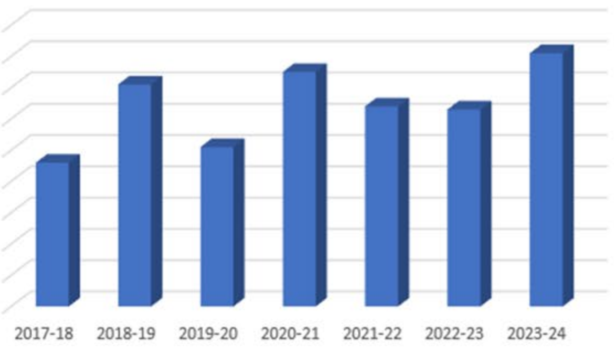
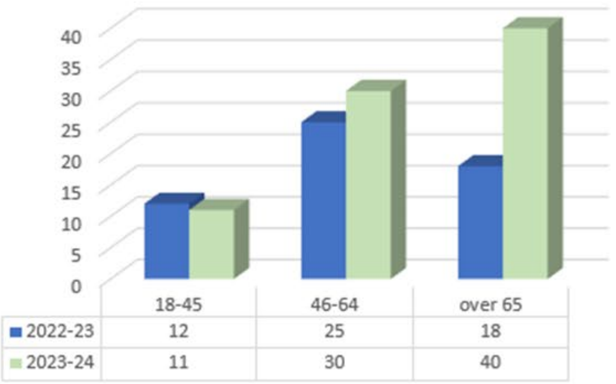


Number of notifications

2



Age at Death Notifications

	18-45	46-64	over 65
2022-23	12	25	18
2023-24	11	30	40

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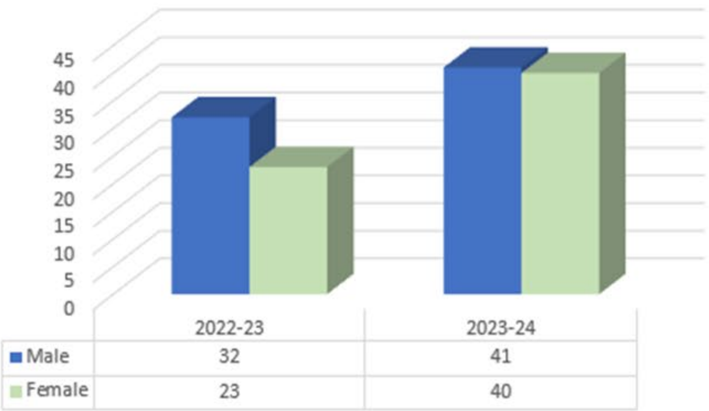

Gender Notifications

	2022-23	2023-24
Male	32	41
Female	23	40

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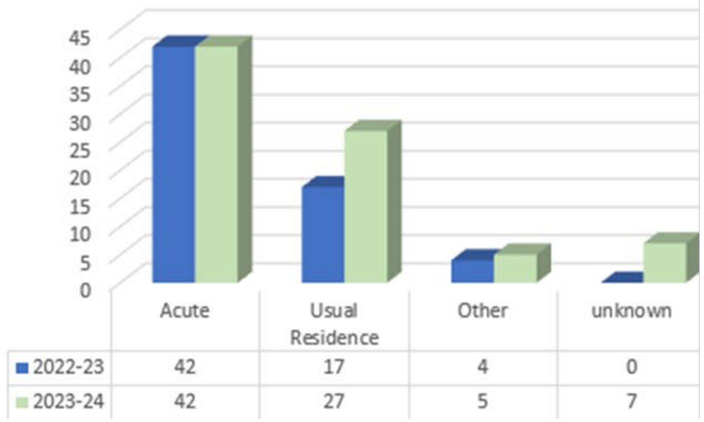

Place of Death

	Acute	Usual Residence	Other	unknown
2022-23	42	17	4	0
2023-24	42	27	5	7

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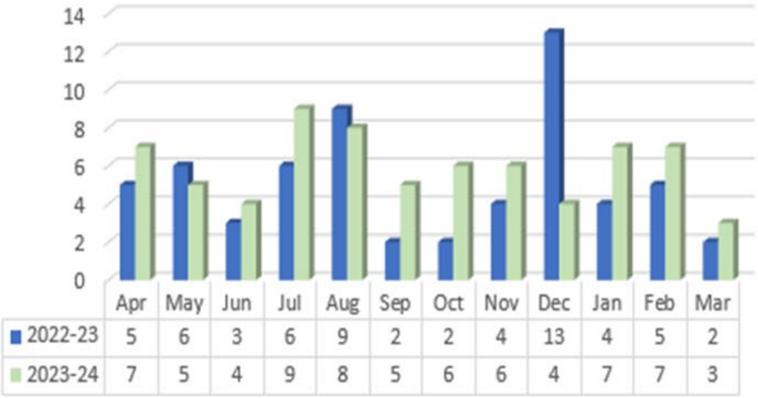

Death by month

	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar
2022-23	5	6	3	6	9	2	2	4	13	4	5	2
2023-24	7	5	4	9	8	5	6	6	4	7	7	3

8. Overview of Completed Reviews

The LeDeR review performance report as at the end of March 2024 shows that 89% (*n*=393) of 444 reviews received since 2017 have been completed by the 2023/2024 year end. The table below breaks down the number of referrals received, and the number of reviews completed every year since the programme began.

Years	No of adult notifications	No of reviews completed	No of reviews carried forward
2017-18	46	3	43
2018-19	71	23	91
2019-20	51	77	65
2020-21	75	77	63
2021-22	63	85	41
2022-23	63	72	32
2023-24	80	56	51
Total	**449**	**393**	

In 2023/2024 56 initial and focused reviews have been signed off as complete. At year end (March 2024), the team have 11 reviews in progress and 40 waiting to be allocated. This includes 5 which are on hold, awaiting statutory processes to be concluded. The team have completed more reviews than previous years as discussed in section 6 but are carrying over more reviews this year and have more reviews waiting to be allocated, demonstrating the increased workload of the team.

For certain variables such as cause of death, avoidable deaths, areas of deprivation and chronic conditions all reviews have been included to get the best breadth of information possible to draw conclusions. Quality of Care grading has only been discussed with the focused reviews as the national policy does not currently require care and service provision grading for initial reviews.

8.1 Initial Reviews

Of the 56 reviews completed in 2023/2024, 30 (55%) were initial reviews.

8.2 Focused Reviews

Of the 56 reviews completed in 2023/2024, 26 (45%) were focused. Most reviews (35%) were converted to focused due to care quality concerns and 23% were converted due to professional judgement, for example if a case is particularly complex. There were many other reasons which individually represented less than 5 reviews, including family request, ethnicity, history of being held under a section of the mental health act, autism diagnosis and local priority.

8.2.1 Quality of Care

The national policy requests that the LIAG grade the care received and the effectiveness and availability of services for all focused reviews. Only focused reviews are graded on the delivery of quality of care and accessibility and effectiveness of services. Grading is based on the information the reviewer has gathered and presented at panel. Of the 26 completed focused reviews from 2023/2024, a higher number of the reviews than last year graded the quality of care as being satisfactory or above (*n*=9). Likewise improving, 65% of reviews demonstrated care which fell short of expected good practice this year, with 10 reviews where this was judged to have impacted the person's wellbeing. At 38%, this again is an improvement on last year. The below table shows the grading of Care for completed reviews for 2023/2024.

Rating	Standard	Number	Percentage
6	This was excellent care (it exceeded current good practice).	0	%
5	This was good care (it met current good practice in all areas).	5	19%
4	This was satisfactory care (it fell short of expected good practice in some areas, but this did not significantly impact on the person's wellbeing).	4	16%
3	Care fell short of expected good practice but did not contribute to the cause of death.	7	27%
2	Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.	8	31%
1	Care fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person.	2	7%

Of the 26 completed focused reviews from 2023/2024, a higher number of the reviews than last year graded the Effectiveness and Availability of Services as being satisfactory or above (*n*=10). Likewise improving, 62% fell short of expected good practice this year with 9 reviews where this was judged to have impacted the person's wellbeing. At 35%, this again is an improvement on last year. The below table shows the grading of Availability and Effectiveness of Services for completed reviews for 2023/2024.

Rating	Standard	Number	Percentage
6	This was excellent Service Effectiveness and Availability (it exceeded current good practice).	1	4%
5	This was good Service Effectiveness and Availability (it met current good practice in all areas).	6	23%

4	This was satisfactory Service Effectiveness and Availability (it fell short of expected good practice in some areas, but this did not significantly impact on the person's wellbeing).	3	11%
3	Service Effectiveness and Availability fell short of expected good practice but did not contribute to the cause of death.	7	28%
2	Service Effectiveness and Availability fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death.	6	23%
1	Service Effectiveness and Availability fell short of current best practice in one or more significant areas resulting in the potential for, or actual, adverse impact on the person.	3	11%

8.3 All Reviews

8.3.1 Age

The table below shows the total number of reviews in each category, since LeDeR began in Norfolk and Waveney. Overall, the 65+ age group still has the highest number of reviews. Potentially because of the 65+ age category seeing a heightened number of excess deaths due to COVID-19 in 2020/2021, due to the added mortality risk of age. Indeed, in the two years from 2021 to 2023, the 46 – 64 age group surpassed it in numbers. Yet this year we are again seeing more deaths at a higher age in both reviews and notifications. The median age of death for all reviews in 2023/2024 was 62 years old, which is an increase of 4.5 years from last year's annual report and is similar to our notification data. As stated in previous years, we are now seeing the impact of a strengthened governance and review process in that our median age of death now more closely matches that of the national picture. The latest national data from 2022 shows 85% of people in the UK population died at age 65 years and over[12], in Norfolk and Waveney 43% of reviews were for those aged 65 and over. This an increase from only 21% last year.

Year of death	Number of Reviews by Age Group (in years)			
	Under 18	**18-45**	**46-64**	**65 and over**
2017-18	0	10	17	19
2018 -19	5	9	25	32
2019-20	<5	11	19	20
2020-21	<5	21	18	33

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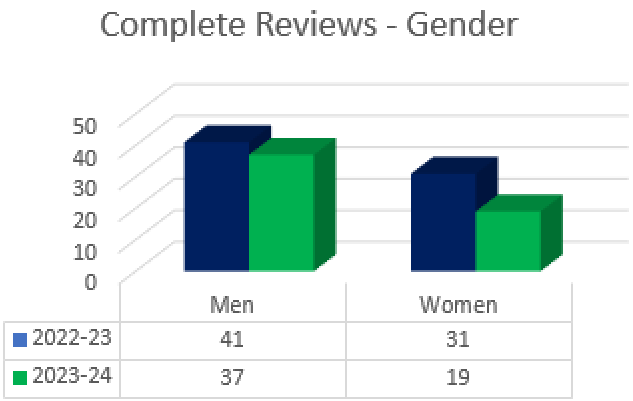
[12] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables

2021-22	<5	10	27	23
2022-23	7	12	25	19
2023-24		11	21	24
Total		**84**	**152**	**170**

8.3.2 Gender

As with our notification data, we had a fairly even split between men and women who had an initial review. Of the 26 focused reviews, most were for men (81%), with only 5 (19%) for women. Last year there were slightly more women having a focused review. Overall, we completed 37 (66%) reviews for men and 19 (34%) reviews for women.



8.3.3 Ethnic Groups

Norfolk and Waveney general population data from 2021 shows 94.9% of people reported themselves to be white, with the broad minority groups representing 5.1% of the population. All initial reviews were for people who were white British, as any person from an ethnic minority would automatically have a focused review as per the national priorities. This year LeDeR completed 2 reviews where the person was not white British (4%). Usually, we would not report on cases numbering less than 5, to protect anonymity, but have done so in this case to highlight our current representations.

8.3.4 Diagnosis

In 2023/2024, 23 (77%) initial reviews had a learning disability diagnosis and 7 (23%) had learning disability and autism diagnosis. All autism only deaths were converted to focused as per the national priorities. Overwhelmingly most of our focused reviews were for people with learning disability only (88%), with most being for men, which is not surprising considering the larger number of men reviewed. We only completed 2 reviews for people with a sole diagnosis of autism. Usually, we would not report on cases numbering less than 5, to protect anonymity, but have done so in this case to highlight our current representations. We have seen our team has received 6 autism only notifications this year, so our expectation is that this number will be higher next year.

8.3.5 Level of Learning Disability Severity

Most initial reviews (37%) were for people with a mild learning disability, followed by moderate (33%) severe (27%) and then profound. Women had a marginally higher representation in the mild category and more men had more severe levels of learning disability, even with a number of women having had a profound learning disability. Of the 24 focused reviews with a learning disability, most were again completed for those with a mild learning disability (42%), but followed by severe (33%), then moderate (21%) then profound. Last year we had more reviews for people with a moderate learning disability, whereas this year we had more reviews for people with a mild learning disability.

Level of Learning Disability	Number	Percentage (*n*=54)
Mild	21	39%
Moderate	15	28%
Severe	16	30%
Profound	<5	xx%

8.3.6 Areas of Deprivation

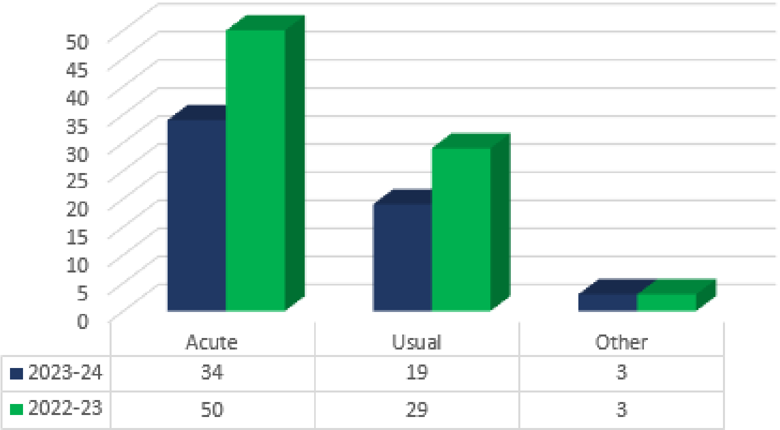
Our local data collection methods allow us to review the Indices of Multiple Deprivation (IMD) for all the completed reviews. As seen in the below table, most people reviewed lived in an area with an IMD score of 6 which is higher than last year, but areas with a rating of 10 were not represented at all in the completed reviews. Overall, as with our notifications for 2023/2024, most of the people we reviewed lived in an area scoring 5 and below on the IMD scale. This tells us people with a learning disability and autism predominantly live in areas of higher deprivation and more so than the general population. However, we have seen a narrowing from 28% to 14%, in the difference between the top and bottom 50%.

IMD Score	Number of Completed Reviews	Percentage	Number of Notifications	Percentage
1	6	11%	32	57%
2	6	11%		
3	5	9%		
4	6	11%		
5	9	16%		
6	14	25%	24	43%
7	5	9%		
8	2	4%		
9	3	5%		
10	0	0		

8.3.7 Place of Death

From our initial reviews, most people died in hospital (63%), followed by the persons usual residence, whether that be a private home, care home or supported living (33%). Our focused reviews reflect the same, with 58% dying in the acute setting. This was the same as last year. However, a reduced number of focused reviews died in combined residential services including care homes and supported living (35%). Overall, most (61%) people died in the acute setting, but at a reduced percentage to last year, and 34% died at their usual residence, which again is a reduced percentage to last year.

Place of Death - Completed reviews



	Acute	Usual	Other
🟦 2023-24	34	19	3
🟩 2022-23	50	29	3

Learning identified from the reviewers:
Although most of the reviews showed people dying in the acute environment, there were several cases where admission could have been avoided with earlier identification of deterioration and better end-of-life planning. Most homes express regret when they are not able to support a person to die peacefully in their home, where familiarity provides reassurances and avoids undue stress.

Appropriate support for staff, robust admission avoidance plans (where appropriate) and good symptom management plans can often mean fewer hospital admissions. Exceedingly good practice has seen some homes going above and beyond to enable a person to die at home with needs that would usually exceed the abilities of a care home. However, these cases were also very reliant on early identification of an end-of-life stage, collaborative planning from the person's multi-disciplinary team and good support from community health services.

It is worth mentioning however end-of-life care in hospital is often managed well, with frequent use of side rooms to offer respite from the busy acute environment. The learning disability liaison nurses are integral to providing this support and are seen repeatedly to be an invaluable resource. Family and carers are often supported and encouraged to accompany the person and oversight from palliative care teams offers excellent symptom and pain management. In one case, a hospital even supported a person's preference to die in hospital, rather than move to a Hospice, as after a prolonged admission they had become familiar and comfortable with the ward staff.

8.3.8 Accommodation

Most people who had an initial review lived independently or in the family home (37%). Supported living accommodated 33% and slightly less lived in a care home (30%). Most people who had a focused review lived in a care home (46%), increasing to 53% when combined with those living in supported living. Slightly less lived in independently or in the family home (42%). Overall, 59% (*n*=33) of people lived in residential services and 39% (*n*=22) lived independently or in the family home. This has reduced from last year where a combined 75% lived in combined residential services. However, this could be reflective of the changes in demographic of learning disability severity this year.

Learning identified from the reviewers:

Most people lived in a supported living or care/nursing home environment. Some issues have been seen such as medication errors and development of pressure areas, but this is not unique to the care of people with learning disabilities and autism. Reviewers are seeing increasing evidence of oversight and monitoring from quality teams where concerns are raised, which appears to support improvements. Reviewers still see problems with homes understanding and adhering to SALT plans, something which is especially important considering the prevalence of aspiration pneumonia.

Availability of suitable accommodation which meets a person's needs, continues to present problems, especially with discharge from hospital. Reviewers have repeatedly seen situations where a Discharge 2 Assess (D2A) bed was sourced in order to enable discharge from hospital, while waiting for a CHC assessment to agree a longer-term living arrangement. Ultimately this means repeated moves for a person, which is often anxiety provoking and presents barriers to staff building familiar and long-term trusting relationships with people which is so important to good health and wellbeing.

Independent housing also presents issues, where oversight is rare, and use of reasonable adjustments is infrequent at best. Reviewers have seen issues with repeated evictions where, despite the person having known vulnerabilities, no one was leading on housing needs or making appropriate referrals for support. Reviewers have seen cases of suspected abuse, including potential "cuckooing" and people being found to have no heating, water or electric within the property. Other reviews have shown poor property upkeep from social housing, including obvious fire risks and hazards which have not been fixed.

8.3.9 Chronic Conditions

Most people with a learning disability and/or autistic people are known to have other complex physical health complications. Analysis of the 56 completed reviews demonstrate all the people we reviewed had one or more chronic physical or mental health condition. This is thought to be due to a combination of factors more likely to occur in people with a learning disability, including congenital conditions, progressive degenerative illness, obesity and poor mobility, difficulties accessing services and many more. The table below is a list of some of the common health conditions and number of people affected, recorded from completed reviews (most people had more than one condition recorded). The single most common comorbidity is still epilepsy, which was recorded in 48% (*n*=27) of reviews. However, cardiovascular was the highest grouping of co-morbidities, with hypertension being the biggest contributor to this. The below tables show the most common single and grouping of co-morbidities. There were multiple other chronic conditions seen in less than 5 reviews which have not been listed here to protect anonymity. For the group comorbidities, the top 10 have been listed.

Single Comorbidity	Frequency	Percentage
Epilepsy	27	48%
Hypertension	14	25%
Type 2 Diabetes	10	18%
Depression	9	16%
Anxiety	8	14%
Constipation	7	13%
Cancer	6	11%
Chronic Kidney Disease	6	11%
Cerebral Palsy	6	11%

Group Comorbidity	Frequency	Percentage
Cardiovascular	34	61%
Mental Health	25	45%
Endocrine	20	36%
Continence	16	29%
Eating and Drinking	12	21%
Muscular Skeletal	12	21%
Developmental Disability	11	20%
Sensory Impairment	10	18%
Respiratory	9	16%
Skin	8	14%

Learning identified from the reviewers:
Reviewers have seen continence care presenting multiple issues over the last year, especially with management of recurrent Urinary Tract Infections (UTI) and catheter care. Often repeat UTI’s are not managed appropriately. Some were not referred to urology for review and others were not prescribed the prophylactic antibiotics recommended. Poor care and monitoring of catheters have been notable. There have been repeated issues with bypassing, blockages and recurrent UTI’s. Catheter

passports are not completed or used appropriately and poor practice in frequency and competency of catheter changes has led to pain, distress, urethral trauma, and incidences of urosepsis.

There are issues with early identification, diagnosis and management of mental health seen by the reviewers. Often opportunities for referrals into secondary care are lacking, even with repeated admissions for serious self-harm. Work is also needed to increase the knowledge and use of adapted assessment tools such as scales to determine depressive, anxiety and/or suicidal symptoms. Pharmacological methods for treating mental health conditions are predominantly used as first line treatment regimens with little evidence seen of any adapted therapeutic approaches such as talking therapy or Cognitive Behavioural Therapy. Little is seen in the way of outcome-based care planning for mental health and where wellbeing services are recommended, self-referral is heavily relied upon with little to no follow up.

Overall, women’s health needs greater focus for people with learning disabilities. Screening is discussed later but also the consideration, recognition and management of menopause is seen to be missing. Reviewers have seen a lot of cases where skin integrity has not been considered in those with limited mobility and there have been multiple reviews which noted the need for safeguarding referrals due to the development of grade 3 and 4 pressure sores. Care homes have experienced difficulties in getting appropriate foot care for people in their care, with podiatry services offering limited reasonable adjustments to those needing home visits and complex cases.

8.3.10 Causes of Death

As part of our post review process, we collate causes of death for all reviews. In Norfolk and Waveney, a review is not signed off as complete unless the Medical Certificate of Cause of Death (MCCD) determination of COD has been seen. A MCCD indicates the sequence of conditions which lead to death, including the underlying, and in turn the leading, cause of death. The leading cause of death is taken from the first line of Part 1 of the MCCD. The World Health Organization (WHO) defines the underlying cause of death as the disease or injury that initiated the train of events directly leading to death or the circumstances of the accident or violence that produced the fatal injury. An underlying cause of death is extracted from the lowest line of Part 1 of the MCCD.

COD can be assigned one of approximately 14,200 codes according to the International Statistical Classification of Diseases and Related Health Problems: 10th Revision (ICD-10). This allows for better comparison between annual reports. Causes of death can then be grouped by code into ICD-10 chapters. Chapters are split according to general types of injury or disease (e.g., Diseases of the Respiratory system).

8.3.11 Leading Causes of Death

In comparison to last year, none of our completed reviews were a COVID related death. This is consistent with the national trend of COVID disease and disease mortality decline.

Year	COVID-19 Deaths
2020/2021	20
2021/2022	13
2022/2023	<5
2023/2024	0

The most common leading causes of death for all of the 56 reviews completed in 2023/2024 are set out in the table below. There were multiple other leading causes of death seen in less than 5 reviews which have not been listed here to protect anonymity. Our completed reviews tell us aspiration pneumonia is the most common leading cause of death for the learning disability community in Norfolk and Waveney. This has not changed from last year. Combined aspiration and other pneumonias accounted for 38% of all leading causes of death in the 56 reviews completed in 2023/2024. Cancer is now the third most common leading cause of death, with all other pneumonias now second most common. Bladder cancer was the most common cancer seen in our 2023/2024 reviews.

Leading Cause of Death	Number	Percentage
Aspiration Pneumonia	11	20%
Pneumonia	10	18%
Cancer	7	13%

The below table looks at the number of leading causes of death by ICD-10 Chapter. There were other chapters allocated to a leading cause of death in less than 5 reviews which have not been listed here to protect anonymity.

Leading Cause of Death Chapter	Number	Percentage
Diseases of the Respiratory System	24	43%
Diseases of the Circulatory System	8	14%
Neoplasms (Cancers)	7	13%

Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	5	9%
Diseases of the Nervous System	5	9%

8.3.12 Underlying Causes of Death

The two most common underlying causes of death for all the reviews completed in 2023/2024 were pneumonia at 18% (*n*=10) and then cancer at 13% (*n*=7). Some underlying causes of death may also be the leading cause of death as there may only be the first line of Part 1 completed on the MCCD. Underlying causes of death are often more varied and as such to protect anonymity only those with above 5 were listed. The below table looks at the number of underlying causes of death by ICD-10 Chapter. There were other chapters allocated an underlying cause of death in less than 5 reviews which have not been listed here to protect anonymity.

Underlying Cause of Death Chapter	Number	Percentage
Diseases of the Respiratory System	15	27%
Diseases of the Nervous System	9	16%
Neoplasms	8	14%
Diseases of the Circulatory System	7	13%

8.3.13 Avoidable Deaths

Avoidable deaths are defined by applying the Organisation for Economic Cooperation and Development (OECD)/Eurostat list of preventable and treatable causes of death[13] using the underlying cause of death recorded on death certificates, for people who died younger than 75 years old. This is the same definition as used by the Office of National Statistic (ONS). Of the 51 Norfolk and Waveney reviews included in this definition 58% (*n*=30) were coded as avoidable. This is a higher percentage than last year but actually represents 2 fewer than the 32 avoidable deaths last year. Yet, this still far exceeds the avoidable death rate of the general population of 23%[14].

Avoidable Causes of Death	Number	Percentage
Treatable	15	28%

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[13] https://www.oecd.org/health/health-systems/Avoidable-mortality-2019-Joint-OECD-Eurostat-List-preventable-treatable-causes-of-death.pdf

[14] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/bulletins/avoidablemortalityinenglandandwales/2020

Preventable	12	24%
Treatable and Preventable	3	6%

Appropriate classifications for causes of death are vital to ensuring these figures are accurate. ONS Guidance for the completion of MCCD[15] state that physical and intellectual disabilities and congenital syndromes which are not fatal in themselves should be avoided in Part 1. Classifications in the first part of the MCCD have been better this year with COD such as “Learning Disability” being seen less, which would also account for the higher avoidable death percentage. Yet we have again seen MCCD including conditions such as Cerebral Palsy and Down Syndrome this year, which can lead to post-mortem diagnostic overshadowing.

Classification was also hindered by use of terms such as “natural causes” which should never be used and “old age” which should only be used very limited circumstances. To maintain the integrity and comparability of the data analysis, the author has strictly followed the coding process used by the regional and national team and assigned these deaths as non-avoidable as per the OECD list. However, were it open to clinical interpretation the avoidable death percentage for Norfolk and Waveney would be higher.

9. Themes, Learning and Recommendations

This section focuses on the findings from the main aspects of care provided to people with learning disabilities and, where data is available, how this compares to other areas. This includes AHC, weight management, overmedication of psychotropic medications, provision of reasonable adjustments, cancer screening programmes and MCA assessments as well as end-of-life care.

9.1 Annual Health Checks (AHCs)

Evidence shows that people with learning disabilities are more likely to experience a greater number of health conditions than the general population. They are also less likely to receive regular health checks or access routine screening[16]. All people with learning disabilities are entitled to an AHC. Regular health checks help identify unmet and unrecognised health conditions, leading to early actions to address and treat these health conditions. Work has been ongoing within primary care to increase the number of checks completed and their quality.

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[15] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1062236/Guidance_for_Doctors_completing_medical_certificates_Mar_22.pdf

[16] https://www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/

Performance for 2023/2024 across the different localities in Norfolk and Waveney, is measured and can be seen in the table below. Notably there is approximately a 12% difference between the best and worst performing areas. This is less than last year but still suggests inequality across the region. Again, there has been an increase in the number of AHCs completed for all people with a learning disability across the Norfolk and Waveney system. Starting in 2019/2020, 63.5% was achieved. This performance went down to 51.5% in 2020/2021, thought to be due to the impact of COVID-19. In 2021/2022, 68% was achieved, increasing to over 70% in 2022/2023 and 74% in 2023/2024.

Locality	# on Learning Disability Register (March 2024)	# of Declines	# of AHC Delivered+	% of AHC delivered*
Great Yarmouth and Waveney	1754	254	1496	75%
North Norfolk	1172	95	1027	81%
Norwich	1548	50	1102	69%
South Norfolk	1459	98	1121	72%
West Norfolk	935	113	779	74%
Total	**6,868**	**610**	**5,525**	**74%**

+Using manual adjustments & automatic reports via CQRS National (April 2023 – March 2024)
**(AHC delivered divided by Declines + Learning Disability Register Total)*

Comparing this with the LeDeR reviews, out of the 54 completed for those who were eligible for regular AHCs, 85% (*n*=46) had been offered an AHC in the 12 months before they died, an increase of 11% on last year. Our post review data collection is also able to tell us that 74% (*n*=40) actually attended their AHC, in the last 12 months before they died, which is again an increase on last year. This means the percentages from LeDeR reviews, now match what we are seeing in the Primary Care and national figures.

AHCs are a foundation of preventative care for people with a learning disability, and an essential part of managing co-morbidities and reducing mortality. Last year, when discussing some of the main themes, we related this to the AHC to reflect how the attendance of a good quality AHC impacts a person's whole wellbeing. This year we are conscious we have 2 autism only reviews. As such, this year we will only review the demographic information of those with a learning disability and interventions you would expect to see at an AHC so as not to exclude anyone.

This year we have a more even distribution of people with different learning disability severities having had their AHC. For those who didn't have an annual health check, this was more likely for those with mild or moderate learning disabilities, suggesting those with more severe disabilities are being reviewed. Although positive, people with mild learning disabilities often have less health oversight and so the AHC remains an important intervention to make sure they don't fall between the gaps in services.

Level of Learning Disability	AHC Completed (*n*=40)	% AHC Completed	AHC not Completed (*n*=14)	% AHC not Completed
Mild	13	33%	8	35%
Moderate	12	30%	<5	xx%
Severe	14	35%	<5	xx%
Profound	<5	xx%	0	0

Those who had received an AHC were nearly 30% more likely to have had an annual medication review. This was higher than last year, with a 13% increase in the number of recorded medication reviews for people who had an AHC. This is an important part of healthcare in that it supports the review of chronic conditions as well as abides by STOMP principles to reduce unnecessary overmedication.

	AHC Completed (*n*=40)	% AHC Completed	AHC not Completed (*n*=14)	% AHC not Completed
Recorded Annual Medication Review	37	93%	9	64%

For those who did not have an AHC in the 12 months before they died, we only knew the BMI for 12. Nevertheless, the average BMI was less, and in the normal range, compared to those who did have an AHC. There are many variables which could impact this including the quality of AHC and the need for proactive weight management in future, the higher severity of disability, prevalence of psychotropic medications and likely higher incidence of physical disabilities and mobility issues in those who had a regular AHC.

	AHC Completed (*n*=40)	AHC not Completed (*n*=12)
Mean BMI	26.2kg/m2	23.3kg/m2

Learning identified from the reviewers:
There seem to be standardised annual health checks, but they appear to be predominantly used as a tick box exercise, not a thorough assessment and reflection of the person's individual situation and needs. Usually, reviews for long term conditions, such as diabetes, are reviewed in a different appointment. However, there would be a benefit to one, longer, appointment which takes a wider holistic view of all the persons health and care needs. Similarly, blood tests are also often organised after a health check, which can lead to a repeat appointment if the results are abnormal. Arranging for blood tests before an annual health check or using Point of Care Testing would allow for better information to assist in health action plans. Where reviews are done well there is a clear benefit to management of long-term conditions, but there are equally poor recordings of annual health checks where reviewers have just seen a set of observations and possibly a weight.

9.2 Health Action Plans (HAP)

A HAP identifies a person's health needs and how best they can be managed, including what the person needs to do, who will help and when this will be reviewed. Completing and providing a HAP is an essential part of a good quality AHC. A HAP is expected to include information such as:

- Health promotion activity
- Weight monitoring
- Referrals to community health, social care, acute and specialist services
- Pain management
- Sight tests
- Dental checks
- Advanced care planning
- ReSPECT paperwork

The person needs to be given a copy, as well as shared with any carers or home environments which may support them. The practice should then scan a copy into the electronic record.

Of the 40 completed reviews where there was an AHC in the last year of their life, 25 (63%) mentioned a HAP was in place. The information from data collected by the Primary Care Team for HAP completion as part of an AHC in 2023/2024 is very different as seen in the table below. Compared to this year's primary care figure of 75%, in 2021/2022 only 56% had a HAP, showing a significant improvement.

Locality	# on Learning Disability Register	# of HAP completed	Percentage*
Great Yarmouth and Waveney	1,754	1,386	79%
North Norfolk	1,172	988	84%
Norwich	1,548	1,035	67%
South Norfolk	1,459	1,063	73%
West Norfolk	935	704	75%
Total	**6,868**	**5,176**	**75%**

** These totals do not include the 161 LD Health Checks claimed by practices via manual adjustments to CQRS since manual adjustment claims do not capture whether a HAP was provided.*

Learning identified from the reviewers:
Although many annual health checks mention a health action plan has been created, no reviewers have seen any in the notes for any reviews. Due to this it is hard to evidence the quality or how detailed or accessible these are. There is no documentation of the outcomes or health goals which have been agreed and no documented review of these outcomes in subsequent appointments. There is also no evidence any HAPs being shared with wider carers or professionals where improving health outcomes may require a collaborative approach.

9.3 Screening

It is of note that we often only receive the last 3 years of primary care notes for a review; therefore, our knowledge of historical screening is limited. So, to give as accurate portrayal of current practice as possible we have only included people who were eligible for the screening at the time of their death in the below analysis.

9.3.1 Abdominal Aortic Aneurysm (AAA) Screening

AAA screening is a way of checking if there's a bulge or swelling in the aorta, the main blood vessel that runs from the heart down through the abdomen. Screening for AAA is offered to men after they turn 65. Of the 13 reviews with these eligibility criteria, only 4 had evidence of a AAA screening being offered, despite 10 having had an AHC in their last year of life.

9.3.2 Cervical screening

Cervical screening is offered to all those with a cervix aged 25-64 years. Invitations should be sent every 3 years up to the age of 49 years and every 5 years up to the age of 64 years. Our reviews did not show any of those eligible had their cervical screening, despite, 5 of the 7 reviews eligible for cervical screening, having had an AHC in their last year of life.

9.3.3 Breast screening

All people registered with a GP as female and aged between 50 and 71 years should have breast screening offered every 3 years. Breast screening involves use of an x-ray test (a mammogram test) to identify any cancers (when too small to feel) plus any other abnormalities in a breast. Despite the low numbers of breast screening uptake as seen below, all the reviews eligible for breast screening, had an AHC in their last year of life.

9.3.4 Bowel screening

Everyone aged 60-75 years should have bowel screening. A home testing kit is sent to a person's home address every two years to collect a small stool sample to be checked for tiny amounts of blood which could be early signs of cancer. Of the 26 reviews, 21 had an annual health check in their last year of life.

The table below shows engagement with national cancer screening programmes. Bowel cancer again has the highest percentage of eligible people screened and has also increased in uptake from last year. This could be because it is the least invasive and can be done at home without having to attend an appointment. Cervical screening had the worst performance from screening of the reviews from 2023/2024, again the same as last year. However, this year we haven't seen anyone have their cervical screening, whereas last year we saw a few. The refusal rate for this intervention was again like breast cancer screening.

Attendance	Bowel (*n=26*)		Breast (*n=10*)		Cervical (*n=7*)	
	Number	%	Number	%	Number	%
Did not Respond	5	19%	1	10%	3	43%
Not Invited/Offered	4	15%	1	10%	0	0%
Screened	15	58%	4	40%	0	0%
Refused	2	8%	4	40%	4	57%

Learning identified from the reviewers:
Cervical screening is usually not undertaken, and it is classed as declined by patient, even when they may lack capacity. Reviewers do not see evidence of reasonable adjustments in undertaking the capacity assessments and if best interest is being considered this is not documented or evidenced. Reviewers have also still seen the screening being declined on the persons behalf as the health professionals deems the person to be not sexually active. Reviewers found breast screening to be more common, however serious service accessibility issues persist for those with atypical body formation or wheelchair users.

Reviewers have found bowel screening can often be used as an investigatory tool in response to symptoms, which may explain why the screening rates are comparatively higher to other cancers. This suggests, on the sole basis of screening, issues with access may still be present. Usually, people are reliant on their carers actioning the invite letter sent to their home and reviewers see too often evidence of care settings ignoring the invite on behalf of the resident, which demonstrates a lack of understanding of the scope of the screening programme. Whether a person has their AAA screening appears to be very much dependent on the surgery they are registered at.

Lack of attendance for screening has been seen due to a bad experiences in the past. Good input from community learning disability teams and preparation for and support in appointments would help counter this. We have seen some informative sessions on screening run by organisations in our area with the support of healthcare professionals, but attendance unfortunately has been very low considering the scale of the problem.

9.4 Vaccinations

We can look closely at the uptake of pneumonia vaccines for those eligible. Chapter 25 of The Green Book of Immunisations[17] states which comorbidities meet the “high-risk” eligibility criteria for the vaccine. Despite recommendations from the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) report[18], Learning Disability is still not included in in this.

Of the 21 reviews, where the persons leading cause of death was a pneumonia, 17 (81%) would have been eligible for a pneumonia immunisation. This is either due to their age or meeting the current high-risk criteria according to the green book. Of

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[17] https://www.gov.uk/government/publications/pneumococcal-the-green-book-chapter-25
[18] https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf

these 17 reviews, 9 had evidence of having a pneumococcal vaccine, meaning 47% didn't. Although still not ideal, this is an improvement on last year. These figures do not include the 2 cases with a leading COD as Sepsis who both had a pneumonia as the underlying COD.

The influenza ('flu') vaccine is a safe and effective vaccine. It is offered every year by the NHS to help protect people at risk of flu and its complications. The flu vaccine is offered to everyone aged 65 and over and everyone under 65 years of age known to have a medical condition that puts them at risk of flu complications. Chapter 19 of The Green Book of Immunisations states which comorbidities meet the eligibility criteria for the vaccine[19]. Uptake of the flu vaccine has also improved on last year, with 86% (*n*=48) of all completed reviews having evidence that the person had a flu vaccine regularly. 46 had been immunised of the 54 who were eligible for and attended their AHC (85%). This is in contrast with only 7% (*n*=4) who had not had a regular flu vaccine but who were eligible for and attended their AHC, highlighting the importance of AHC on public health initiatives and preventative care.

The COVID-19 vaccine is a safe and effective vaccine and began distribution from December 2020. Those with a learning disability and associated co-morbidities were highlighted as being more at risk from severe COVID-19 complications and, as such, fell into the priority groups for being offered the vaccine. The first vaccines were rolled out in January 2021. All the completed reviews had a date of death after the third dose was offered from the beginning of October 2021 and 89% (*n*=50) had evidence of 3 or more covid vaccines, which again is an improvement on last year.

COVID Doses	Number
0	3
1	1
2	2
3	18
4	19
5	13

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[19] https://assets.publishing.service.gov.uk/media/654cf306014cc90010677371/Green-book-chapter-19-influenza-_3November2023.pdf

Learning identified from the reviewers:
Reviewers have continued to see good COVID vaccination coverage and continued high uptake of the yearly flu vaccination. Reviewers have suggested a higher uptake of the pneumonia vaccine which is evident in the data and good to see. However, reviewers still identify people with health co morbidities who would benefit from this vaccine, did not receive this vaccine.

9.5 Obesity/Weight Management

When a person carries excess weight or body fat it can affect their health. Evidence shows that people with learning disabilities are more likely to have a poor diet and are more likely to be underweight or obese than people in the general population[20]. The Body Mass Index (BMI) is a measure that uses a person's height and weight to calculate whether their weight is healthy. BMI should be used with caution for those with learning disabilities as certain co-morbidities can impact someone's weight such as chronic constipation. It can also be difficult to accurately capture measurements for people with an atypical body shape or poor posture (postural kyphosis) which are more common with persons with a learning disability. The BMI tool is currently the most used and acceptable measure of weight and health, but some other options could include waist circumference or measuring a fold of skin. BMI categories can be seen below:

- <18 is underweight.
- Between 19 and 24.9 is healthy.
- Between 25 and 29.9 is overweight.
- >30 is obese.

Being underweight or overweight raises the risk of serious health problems and is known to have a direct impact on the person's quality of life. The table below shows the outcome and analysis of data of BMIs recorded for the 56 reviews.

Gender	BMI (kg/m2)									
	<18	**%**	**19-24**	**%**	**25-29**	**%**	**>30**	**%**	**Unknown**	**%**
Males (*n*=37)	3	8%	16	43%	7	19%	10	27%	1	3%
Females (*n*=19)	3	16%	8	42%	3	16%	5	26%	0	%

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[20] https://www.gov.uk/government/publications/obesity-weight-management-and-people-with-learning-disabilities/obesity-and-weight-management-for-people-with-learning-disabilities-guidance

Total (*n*=56)	6	10%	24	43%	10	18%	15	27%	1	2%

In the 56 completed reviews both men and women mostly had a healthy BMI recorded. However, last year men had a higher percentage in the 19-24 range than even the overweight and obese categories combined, which is not the case this year. Yet, in a change from last year women have a lower combined percentage of people who were overweight or obese. There were again more women, as a percentage, who were underweight than men. Overall, most percentage representations in the age groups were similar to last year except the >30 group which was higher. However, we have far less reviews with unknown BMIs than last year, which may account for the change.

Learning identified by reviewers:
Although the review data shows that on average weight falls into the higher end of normal weight, where weight management is an issue, it has a big impact on wellbeing. Reviewers identified that being overweight or obese was a common issue amongst people with a learning disability and this is complicated by diet, poor mobility and/or wheelchair dependency. Obesity is leading to type 2 diabetes and then poorly managed diabetes is leading to chronic kidney disease, retinopathy, and recurrent infections. In managing weight, there seems to be a general advice for healthier lifestyle at AHCs including uptake of exercises and healthier diet. However, this is rarely adhered to or monitored, and referrals to specialist support is infrequent. Another issue seen in the lack of appropriate scales available in the community, either at GP surgeries or in care homes. Adapted scales are needed for those who require hoisting or wheelchair/sitting scales and when not available, often weights are just not done.

9.6 BMI and Psychotropic Medications

Psychotropic medicines are used for psychosis, depression, anxiety, sleep problems, epilepsy and sometimes given to people because their behaviour is seen as challenging. Weight gain can be associated with use of psychotropic medicines including antidepressants, mood stabilizers and antipsychotic drugs[21]. Of our completed reviews, 39% (*n*=22) had evidence of psychotropic medications being prescribed, this is a reduction of 14% on last year.

It is suggested that patients with a BMI of 25 or over should be regularly reviewed and where appropriate, supported to stop or reduce psychotropic medicines. In all our reviews recorded as being on a psychotropic medication, 50% (*n*=11) had a BMI

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[21] https://www.bap.org.uk/pdfs/BAP_Guidelines-Metabolic.pdf

considered overweight or obese, which is higher than last year. Again however, this may be due to better recording of BMI in our reviews.

9.7 Stopping Overmedication of People with a Learning Disability (STOMP)

STOMP[22] is about helping people to stay well and have a good quality of life by stopping the overuse of medicines for those with a learning disability and/or autism, mainly comprising psychotropic medicines. Long term psychotropic use with epilepsy is expected. This is often a first line treatment and effectively managing epilepsy is essential at avoiding Sudden Unexplained Death in Epilepsy (SUDEP). However, 77% (*n*=17) of people who were prescribed psychotropics, had them for a mental health condition or to support in behavioural management, and 76% of those (*n*=13) had been on psychotropics for over 5 years.

The most common singular reason for a psychotropic being prescribed was due to a mental health diagnosis, present in 11 (50%) reviews. 27% (*n*=6) had multiple psychotropics prescribed for multiple diagnosis, mostly this was a diagnosis of epilepsy with a mental health condition and/or behaviour management. Less than 5 reviews had psychotropics prescribed for a sole diagnosis of behaviour and then epilepsy.

Most people prescribed psychotropics had a mild learning disability, followed by moderate and then severe. The table below shows the findings from completed reviews. Last year a total of 53% of reviews were prescribed psychotropic medications, this year 39% of reviews had psychotropics prescribed.

Learning Disability	Mild	Moderate	Severe	Profound
Psychotropics prescribed	9	8	5	0
Percentage	41%	37%	22%	0%

Learning from the reviewers:
Reviewers have seen many cases where antipsychotic medication was prescribed many years ago where the person does not have a mental health diagnosis and they are not open to mental health services. Meaningful medication reviews for antipsychotic medications are not satisfactory and shared care arrangements to ensure specialist reviews of mental health medications are not in

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[22] https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/

place. It is often documented in GP records that medication reviews have taken place, but it is unclear what this involves and the quality of this review. Good practice has been seen in primary care where reviews have shown good evidence of medications being reviewed and psychotropics being stopped when they are not of benefit. The best practice in prescribing and in adherence to STOMP principles has been seen with the involvement of the community learning disability psychiatry team.

9.8 Mental Capacity Act (2005) Assessments and Restrictive Legislation

Mental Capacity Act (MCA) assessments are applied to people aged 16 years and over. The aim is to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. The MCA covers a wide range of decisions such as day to day decisions on what to wear, personal care, where to shop, to significant and serious life-changing decisions such as changing homes, major surgery, and financial management.

The MCA states[23]:

- Assume a person has the capacity to make a decision themselves, unless it is proved otherwise.
- Wherever possible, help people to make their own decisions.
- Do not treat a person as lacking the capacity to make a decision just because they make an unwise decision.
- If you make a decision for someone who does not have capacity, it must be in their best interests.
- Treatment and care provided to someone who lacks capacity should be the least restrictive of their basic rights and freedoms.

It is expected that all our reviews for people with a learning disability (n=54) would have required a capacity assessment at some point in their care. From the reviews 61% (n=33) had evidence of a capacity assessment being completed, 20% (n=11) of reviews described adherence to the MCA as variable, and 19% (n=10) reviews had no evidence of a capacity assessment having been completed at all. This performance is worse than last year.

Learning from Reviewers:

Reviewers find that usually the MCA is appropriately and effectively used in acute settings, although good documentation is still an issue. The voice of the person at the centre of the decision is usually lost and consideration of their experience, feelings and values is

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[23] Section 1 of https://www.legislation.gov.uk/ukpga/2005/9/contents

missing. It has been noticed that if the patient is deemed to lack capacity and needs a best interest meeting to make a decision, there seem to be significant delays which is detrimental to the patient. Allocation of an IMCA still takes too long, which is not good practice when a decision needs to be made for the individual. Good practice is best exampled when the need for the MCA is identified early and a collaborative decision-making process involving all necessary professionals is undertaken. As with other areas of care, acute compliance with the MCA is most seen when learning disability liaison teams are supporting the process and advocating for the person. MCA is rarely seen in primary care, but is often referenced and documented by community care services who may be visiting home to take bloods or provide wound care etc.

9.9 Deprivation of Liberty Safeguards (DoLS)

DoLS ensure people who cannot consent to their care arrangements (i.e., in a care home or hospital) are protected if those arrangements deprive them of their liberty. Arrangements are assessed to check they are necessary and in the person's best interest. Representation and the right to challenge a deprivation are other safeguards that are part of DoLS. This safeguard is also appropriate if a person lives in supportive living or in their own home and is under 'continuous supervision and control'. The point of the authorisation is the same as in a care home or hospital, and the same criteria apply. However, the process is slightly different. Most reviews highlighted that DoLS had not been used when it was required to safeguard a person's liberty.

DoLS Used	Number	Percentage
Yes	10	19%
No/Not Stated	39	72%
Not Applicable	5	9%

Learning from Reviewers:
Reviewers have seen evidence of hospitals applying for emergency DOLs, but in the community very few cases have the safeguards in place. Processes are heavily delayed due to capacity issues

9.10 End-of-Life Care

End-of-life care is also referred to as palliative care or advanced care planning. It involves conversations between people with learning disabilities, their families, and carers and those supporting them about their future wishes and priorities for care.
Out of all the completed reviews, 33 (59%) had evidence of the person being on an end-of-life plan before they died, similar to last year. The length of time on an end-of-life care plan varied from a couple of days to over 6 months. A higher percentage of people

who died on an end-of-life care plan, died in the acute setting. This year we didn't have any deaths in a hospice setting, potentially as we no longer review the lives and deaths of children. There is no data available to indicate whether people's wishes were observed in all settings.

	Place of Death							
End-of-life Pathway	Acute	Percentage	Usual Residence	Percentage	Hospice	Percentage	Other	Percentage
Yes (*n*=33)	22	67%	11	33%	0	0%	0	0%
No (*n*=23)	12	52%	8	35%	0	0%	3	13%

Learning from the reviewers:
There are a growing number of cases who despite being at an end-of-life stage, end up in hospital for symptom management. With appropriate planning and support for palliative care and clear care plans this could be avoided. Reviewers have seen good examples of excellent end-of-life planning including consideration of a person's preferred place of care, with the option to die at home in familiar surroundings, but often because of a rapid decline this was not possible. Reviewers have also seen multiple issues around not having anticipatory medication and necessary paperwork in place to allow community teams to administer care, suggesting primary care need to be referred to and engaged earlier in the planning process.

9.11 Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

The Recommended Summary Plan for Emergency Care and Treatment[24] (ReSPECT) process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices. It would be reasonable to expect everyone who we reviewed to have had a ReSPECT form in place, when they died.
Out of all the completed reviews 42 (75%) had evidence of a completed ReSPECT document at the time of their death which is very similar to last year, but with a slightly higher percentage of those with a ReSPECT form having died in hospital (69%). As previously mentioned, ReSPECT is a discussion which should happen as part of the AHC. According to reviews, 79% of those who had a ReSPECT document completed, had attended an AHC in the last 12 months of their life, a higher percentage than last year.
Of the 33 people who were on an end-of-life plan, 97% had a ReSPECT form completed. This is compared to only 39% of those

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[24] https://www.resus.org.uk/respect/respect-healthcare-professionals

who were not on an end-of-life plan. Suggesting although ReSPECT may be being better used in those at end-of-life, work is still needed to make full use of its design as an emergency care planning document.

Learning from the reviewers:
Reviewers are still seeing hospital ReSPECT forms used primarily as a DNACPR, where completion is poor, and evidence of MCA adherence is lacking. Reviewers have seen more ReSPECT forms being completed in the community which is good, but rather than review and update these on admission, they are often re-done, to a lower quality. We often see good involvement of families, but too limited consideration for adapted ways of involving the actual person in decisions being made about their care. Where there is permanent and severe impairment to the functioning of the brain, little is documented to give the person a voice and demonstrate their values or wishes have been considered. Where ReSPECT forms are used as intended, reviewers see excellent examples of a fully completed forms with clear care plan for avoiding hospital admissions, which significantly improved a person's quality of life.

9.12 Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

The guidelines state that it is good practice for decisions about DNACPR to be clearly communicated to all those involved in the patient's care. It is important that healthcare professionals, patients, families and those close to patients understand that a DNACPR decision applies only to cardiopulmonary resuscitation (CPR) and not to any other element of care or treatment. A DNACPR decision must not be allowed to compromise high quality delivery of any other aspect of care. Out of all the completed reviews 43 (77%) patients had a DNACPR order in place before they died, with 93% of these being deemed appropriate according to the evidence available. This is much improved from last year.

Learning from the reviewers:
Reviewers feel that overwhelming DNACPR orders are used appropriately and, in the persons best interest, with conversations with family and key carers frequently seen as good practice. However, documentation how decisions were made continues to be poor with little evidence of adherence to the MCA.

9.13 Reasonable Adjustments

Making reasonable adjustments is a statutory duty under the Equality Act 2010. This states that all health and social care providers must make reasonable adjustments to remove any barriers, physical or otherwise, that could make it difficult for disabled people to use their services or prevent them from using them altogether.

A lack of reasonable adjustments can be a significant barrier to accessing healthcare and healthcare settings. Reasonable adjustments are not just stand-alone interventions and are woven into people's daily care and support. Below are highlighted some of the themes seen in reviews, regarding good provision of reasonable adjustments and where practice needs improvement. Looking at the reviews examined, reasonable adjustments fell into multiple themes, which were either accommodated or not, and are summarised in the tables below.

Theme	Examples of good use of reasonable adjustments
Adapted Access	• Primary Care visits at home or outside of the practice to encourage engagement. • Environmental controls such as side rooms, especially used for end-of-life care. • Changing appointment times to ensure face to face contact. • Home visits by hospital staff to help prepare for interventions. • Use of hospital passports and emergency admission plans. • Clinician follow up as part of a "was not brought" policy following non-attendance at appointments. • Acute Learning Disability Liaison Teams. • District nurse visits to day centres to deliver care which wasn't possible at home. • Supporting home between ED attendance and surgical review the following day to reduce anxiety.
Communication	• Information provided in clear, concise, and simple language. • Easy read care plans provided by primary care in collaboration with patients. • Plans for end-of-life care produced with the input of patient using adapted methods to gain their wishes and views. • Use of community learning disability nurses to support communicating a terminal diagnosis and provide reassurance. • Appointment invitation letters in easy read. • Provision of communication care plans. • Adapted communication which meets individual needs. • Time allowed for processing.
Familiar Carers	• Parent/carers are supported to stay with their children while admitted. • Using care staff to support with end-of-life care. • Involving familiar carers in best interest decision making. • Allowing community care staff into the acute care environment.

	• Staff are encouraged to attend appointments with people for support and advocacy. • Flexibility in visiting times for family and carers.
Bespoke Care	• Adequate planning and individualised care to support interventions such as blood tests. • GP overrode a person's need to attend a specialist clinic on a different site as they engaged well at surgery, and it was causing undue stress. • Non pharmaceutical methods to aid anxiety and agitation. • Flexible service provision to provide continuity of care by staff familiar to the patient. • Collaborative needs-based care planning. • Shortened hospital admissions with increased community-based follow up interventions. • Admission plans include strategies to reduce overly restrictive and restraint practices. • Care home taking on complex end-of-life care to enable a person to die in their home. • Good response to soft signs of deterioration.

Theme	Examples of poor use of reasonable adjustments
Adapted Access	• Lack of referrals to specialist learning disability teams due to poor diagnosis coding, delaying support. • Services requiring intensive and time-consuming advocacy from professionals to deliver reasonable adjustments including home visits. • No annual health check provided to a person as they were not able to attend the surgery and no alternative was offered or provided. • Service referral and triage processes not adapted to accommodate a person with a learning disability, meaning multiple discharges without a person being seen. • No admission plans to avoid busy and distressing environments which can impact concordance with care.
Communication	• Lack of access to easy read and simple language information and communication for people who require it. • Lack of adapted communication to aid and assess understanding including for invasive surgical procedures. • Where a person had refused care, additional time to communicate effectively and allow time for processing may have helped.

MCA Principles	• Limited use of MCA principles in decision making about cancer screening. • No reasonable adjustments used to enable a person to understand or contribute to the completion of their ReSPECT form. • DNACPR forms completed with little to no evidence or documentation of how the decision was made and how the person voice was represented. • Poor evidence of MCA principles being used to inform someone's living situation. • Poor adaptive communication to best assess someone's capacity when they decline important health interventions. • Best interest meetings may not always need to be strictly formalised, but documentation is required to evidence the work.
Provision of Care	• Frequent changes in home lead to inconsistent care and little oversight of health and wellbeing. • Referrals into our area from out of county are poor with little communication on history, needs and goals. • Lack of adaptions to service provisions have created barriers to engaging in care, especially for those with more complex social situations. • Poor collaborative working between services has resulted in gaps in care planning, highlighting deterioration and assessing risk. • Required cancer home screening processes were not supported or facilitated by community care providers. • Follow up for missed or declined screening appointments is lacking. • People are not added to learning disability lists so not invited for annual health checks. • Availability of respite facilities that can meet the needs of people with complex health needs is poor.

Use of reasonable adjustments is variable across the different reviews examined for this section. There is also evidence of variability within the same reviews and some cases showed evidence of multiple adjustments to make services more accessible and a lack of adjustments which have created barriers for people to access the care they need. Overall, there is definitely evidence of more use of reasonable adjustments than not. Last year we had several reviews where reviewers did not see any examples of reasonable adjustment being used, this year we didn't have any. Although highly subjective, this is still perhaps a good indicator of progress. Especially as it is notable that the number of reviews with examples of missed reasonable adjustments has fallen.

Learning from reviewers:
Reasonable adjustments are hard to measure as each person's needs are different. Some are very clear and obvious whereas others are subtle. Overall, there was a prevalence in reasonable adjustments being used. This was predominantly led by learning disability specialist staff in acute and community settings. The value of these colleagues cannot be underestimated and is evidenced in the reviews. The best way to identify and communicate what adjustments are needed is by having updated care plans such as hospital passports, health action plans and ReSPECT forms. These should be electronically added to someone's file where possible. Reasonable adjustments are usually something that needs to be asked for, which isn't easy or possible for everyone. A good roll out of the Reasonable Adjustment Digital Flag will open up accessibility from the very first contact with services.

10. Safeguarding

Reviewing the deaths of people known to have a learning disability and/or autisitic people helps ps identify avoidable factors that lead to early deaths and supports services to improve their quality of care. This is a major step forward towards tackling inequalities within health and social care provision. As part of the review process, safeguarding is always a consideration and forms the foundation for any case discussions the team has. The national LeDeR policy provides a robust governance process for safety and abuse concerns to be highlighted, and the Norfolk and Waveney team has been structured to meet this.

A review will often be presented at multiple panels for Quality and Assurance checks and sign off. This allows the multi-agency panel the opportunity to go beyond the remit of LeDeR and promote challenge, assurance, and service improvement. In addition, the team has structured its local arrangements through guidance co-authored with the ICB designated safeguarding team and the Norfolk Safeguarding Adults Board (NSAB).

This has proceeded the agreement of appropriate safeguarding training and supervision for the LeDeR Team as per the collegiate document[25] and a structured process for referring for Safeguarding Adult Reviews (SAR). The Senior Nurse Manager and LAC for the LeDeR programme also presents the findings of reviews to the ICS Learning from Death Forum every quarter, to share key learning with representatives from the wider NHS providers and the ICB's Safeguarding Team.

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[25] https://www.rcn.org.uk/Professional-Development/publications/adult-safeguarding-roles-and-competencies-for-health-care-staff-uk-pub-007-069

Over the last year our team has had five cases go to NSAB to be considered for a SAR. For LeDeR, the basis for a SAR is to learn lessons from particularly complex or serious safeguarding adult cases, where an adult has died, and abuse or neglect has been suspected. If the referral is accepted a detailed review is undertaken and, recommendations are made to change or improve practice and services.

Learning from reviewers:
Reviewers have found that some safeguarding investigations can take a long time if the individuals are deceased, this can delay the LeDeR review process. There are also some incidences where safeguarding outcomes are not documented on systems. Some retrospective safeguarding enquiries were also declined on the premise that the individual is no longer at risk due to their death. Looking at the wider impact of safeguarding on care environments, it is important to investigate where poor care for one may impact poor care for others.

Likewise, reviewers have seen multiple instances of missed opportunities to refer to safeguarding, including vulnerable people who have been assaulted multiple times, people living in poor living conditions and people at risk of county lines related crime. Reviewers have also seen a lack of professional curiosity from services when concerns are raised, taking reassurances at face value from people who may lack capacity.

Collaborative working has shown to impact health and wellbeing in a few cases which have required SAR referrals. In some instances, reviews have been submitted together due to very similar themes. An overview of a person's health action plan is important for all professionals to work in an outcome and goal focused way. This is also a good way to monitor quality of care and the degree to which people are being supported to access screening appointments, get their vaccinations, manage their weight, attend chronic conditions appointments etc. When this is consistently missed, safeguarding should be considered.

11. Examples of Lived Experiences

This section is about the stories of people who have died. They have families and friends who cherished their lives and whose deaths will never be forgotten by their loved ones. Therefore, we are sharing some of the stories and experiences from completed reviews. This information has been provided by family members or carers who knew the person well. The details have been anonymised and names changed to further protect their identities.

Hazel

Hazel was a 27-year-old woman who lived with her family. She was a keen Park Runner, and enjoyed reading, doing jigsaws and had a wonderful sense of humour. Before COVID, Hazel had a job working in a charity shop, which she really enjoyed, but found it hard to return after the lockdowns. Hazel found the pandemic very difficult due to the restrictions and her anxieties around her health. Hazel had two of her COVID vaccines but had a third dose declined on her behalf with no consideration of capacity or best interest decision making.

Hazel had great support from her epilepsy nurses and was seizure free for the 6 months before her death. Hazel did have depression but was never seen by wellbeing services despite being referred when she was diagnosed. Her anti-depressant medications were poorly managed and for at least three years, due to an unmanaged weaning process, Hazel was on a suboptimal dose of both an SSRI and an SNRI. NICE guidelines suggest these should be prescribed with caution in patients with epilepsy.

Overall, Hazel’s review demonstrated how little her voice was considered by the professionals working with her, and it is not clear Hazel ever had the opportunity to speak to professionals on her own, so that her wishes and aspirations could be fully understood.

Mitch

Mitch was a 72-year-old gentleman who lived in his own home. Mitch used to work as a forklift driver but retired after being made redundant a few years back. Mitch was very proud man, with a great sense of humour and loved to tell funny stories. He liked to watch TV and read the newspaper every day. Mitch had a very close relationship with his mum, who he lived with before she sadly died 10 years previously. Unfortunately, Mitch had struggled to take care of himself in the following years and had no other family looking out for him.

Mitch was referred to the community learning disability team and then social care after a visit to the GP. A home visit found he was living in a neglected environment which was unclean, with no heating, no electricity and he was eating food which had gone off. Within 6 weeks his house had been deep cleaned and all his white goods replaced. He had also been supported with his finances and banking, to make his money safe and helped with future planning.

After being diagnosed with cancer, Mitch had incredible support from his community and hospital learning disability teams, who worked very closely with other specialties to make sure he had the care he needed. His GP practice had a very good approach to reasonable adjustments and helped Mitch by supporting him to read letters, ensured he was aware of where his appointments were and providing easy read Health Action Plan.

Thomas

Thomas was a 65-year-old man who lived in a supported living environment with high levels of care. Thomas had lived in institutions for much of life. When these closed down he moved into more community-based settings. Thomas was beloved by all the staff at his home. Thomas had had a great sense of humour and he loved dogs, food, and his family. In that order according to his sister. He also enjoyed listening to music, going out on trips and holidays with the staff, and when he was well enough, visiting his family who all lived around the country. Overall, Thomas liked nothing more than siting with a cup of tea and people watching.

Thomas had deteriorated in the 2 years before his death. The GP had arranged for a ReSPECT form which was discussed with Thomas' family. However, the reason for a DNACPR decision was recorded as being because Thomas was "non-verbal" and had a "learning disability". Thomas had a few hospital admissions in this time which he found very distressing, despite the hard work from the acute learning disability liaison nurses who had worked hard to keep him comfortable.

His ReSPECT form was reviewed, updated and a plan was made in Thomas' best interest to avoid future hospital admissions because they were unlikely to result in any positive outcomes. This significantly improved the quality of Thomas' life. The support of the community teams was invaluable in keeping him out of hospital and managing his symptoms at home. It was testament to everyone involved that Thomas was able to stay in his familiar surroundings and with familiar staff until his death. It was unusual for the care home to provide end-of-life care, but their hard work and the support of the palliative care team made it possible.

Phoebe

Phoebe was a 46-year-old lady who lived at home with her mum, who was her main carer. Phoebe liked sensory stimulating experiences, being out in nature, and being in the swimming pool. Phoebe attended a day centre 5 days per week, which she loved, but following the pandemic her family felt the availability of services and activities that she used to have, had gone.

Phoebe had complex learning and physical disabilities meaning she needed support from multiple services and was completely reliant on her mum as a primary carer. Phoebe was born with a genetic developmental condition, with which she was not expected to live beyond 2 years old. Yet she did, and it was clear from the review just how much her mum's expert and dedicated care and attention contributed to Phoebe reaching the age she did. Phoebe's mum told us she tried to make every day as good as possible for her, and tried to think how she could experience everything. She spoke to Phoebe all the time and told her she loved her every day.

Overall, the staff involved in Phoebe's life were very caring and dedicated. However, Phoebe’s family did find professionals work is largely hampered by bureaucracy and red tape, which had worsened since the pandemic. Ultimately this impacted Phoebe’s access to the equipment and services that she needed in a timely manner. For example, the GP practice not providing reasonable adjustments by way of annual health checks at home. Or difficulties and delays in adjusting her wheelchair and provision of a shower chair, which were essential parts of Phoebe’s health and wellbeing. Staff turnover increased which was frustrating for the family because there was no consistency for Phoebe and the quality of her care at home was impacted. Post pandemic there was a decrease in face-to-face contact, which Phoebe’s family felt resulted in care and understanding being lost.

Phoebe sadly died at home following a short illness. Her family received over 300 condolence cards, showing how many lives Phoebe had touched.

Daniel

Daniel was a 50-year-old gentleman who enjoyed watching TV, listening to music, cooking, drawing, video games and playing or watching others playing pool. He had lived in Manchester before moving to Ipswich with his partner, where they lived for 20 years until his partners death. Following this, Daniel had periods of homelessness and a history of alcohol and substance misuse and mental health difficulties, which required hospital treatment under section. In 2019 he was admitted to hospital under a Ministry of Justice section of the mental health act.

Daniel had regular Care Programme Approach (CPA) meetings to establish where he was on the road of recovery and set future goals with aim for discharge. Daniel had extreme anxiety about discharge because in his mind that meant that he would be left without support and made homeless. For this reason, he declined having Section 17 leave for some time during his admission. With support and reassurance from staff he accepted the leave while looking at a possible discharge and a search for a suitable placement was started. When a home was sourced, discharge planning was done carefully and included a transition period as well as a coordinated support and community follow up from a specialist forensic learning disability team and mental health care coordinator.

Daniel was very well cared for in hospital, where his physical health needs were met as well as his mental health needs. He was eventually discharged to a care home, which was carefully planned and coordinated. His handover to community mental health teams was well done with a clear change in care coordination and responsible clinician. His new home was at a placement of Daniel’s choosing after he had visited several different settings. There was a transition period where Daniel visited the care home three times a week and had an overnight stay to get accustomed with staff and the environment. Unfortunately, he only lived there for 2 weeks before being admitted to an acute hospital after becoming unwell, and sadly passed away.

Pamela

Pamela was a 79-year-old lady who lived independently. She had attended a specialist school and later spent time working in the laundry industry. Pamela had been married but lost her husband some time before her death which had a detrimental effect on her life and mental wellbeing. Pamela liked to knit, draw, and complete crafts. She also took part in cooking lessons at the day centre she attended twice a week, before COVID. During the lockdowns the centre’s staff were incredibly supportive with wellbeing calls and visits. Unfortunately, this centre closed in 2021, and this left a gap in Pamela’s life as she had formed close bonds with both staff and other service users. Pamela tried to remain in close contact with her friends from the hub, and they used to go shopping together, but this was harder to do.

Pamela had close friends but due to their ill health contact reduced and her family had concerns Pamela was becoming increasingly isolated and lonely. A befriending service was arranged by the local authority but there was no suitable alternative to the centre following its closure. Pamela did not have a face-to-face Care Act Assessment following her changes in circumstances and family concerns being raised. This could have better identified similar services which provide a vital source of friendship and fulfilment. Closure of services needs to be seen as a risk to health and wellbeing, with relevent steps taken to replace what has been lost.

Pamela’s GP were very good at helping Pamela with her appointment letters and the staff on reception would often help her by explaining what letters were and what she needed to do. Despite this additional support however Pamela was never diagnosed as having a learning disability and was not added to her GP’s learning disability register, as such had never had an annual health check. Pamela became unwell at home as was admitted to hospital. Unfortunately, she didn’t respond to treatment and so end-of-life care was commenced with a focus on comfort and symptom management.

Evan

Evan was a 54-year-old gentleman who lived in supported living with 24-hour support. Evan was gentle, content, and happy. He was very social and loved to be around people. He had a mobility car and loved going out for meals, visits to the city centre, cinema, shopping and museums. He enjoyed being in the company of people and liked to sit in a café watching the world go by. Evan had recently gone on a cruise to Norway for his 50th birthday which he had really loved.

Evan required support from familiar staff for all his health and care needs. Evan has lived in his home for 30 years, and most of the staff had known him a very long time and were familiar with his needs and worked exceptionally to keep him well and able to peruse his interests and passions. When Evan became unwell, carers spotted this early and liaised with the GP who advised admission to hospital. Evan was found to be very unwell with an acute bowel obstruction, likely due to cancer. While in hospital Evan had a lot of support from the acute learning disability liaison nurses and continued to have his familiar care staff with him.

A cross speciality medical discussion was had which agreed invasive intervention was unlikely to be in Evan’s best interest and palliative care was started. His staff were kept up to date after the decision but there is little documentation of any wider involvement in this best interest decision outside of clinicians. Neither was their evidence of an Independent Mental Capacity Advocate being used to inform this decision. Evan deteriorated quickly and sadly passed away a few days after his admission, with his key carers by his side.

Claire

Claire was an 84-year-old woman who lived in a care home. Before her stroke Claire was a very active person. She used to go to a day centre several times a week and participated in activities organised there. She loved reading and helped with the mobile library. Claire was involved with a local church which she attended every week, and sometimes did the readings. Claire loved music and dancing and even went to a group to learn flamenco dancing.

Claire had lived in her home for nearly 30 years. Her care staff were very familiar with her needs, and they provided excellent support in managing her multiple comorbidities. Claire had epilepsy and two years after her stroke had a severe epileptic seizure leading to a cardiac arrest. Claire was resuscitated but was left frail and was discharged home on end-of-life care and with an admission avoidance care plan.

Claire remained frail, though her condition stabilised over the next few years until the year of her death when she became more unstable. Claire had regular palliative care reviews from her GP surgery, and anticipatory medication was prescribed. Her care was focused on comfort and symptom management and although she was referred to community palliative care team, she never required assistance from them as her symptoms were so well managed by her home. Claire passed away in her own home with her carers by her bedside.

Anna

Anna was a 19-year-old young lady who lived at home with her family. Anna attended a special needs school and required support in meeting all her care needs. Anna required an intensive and complex care regime to keep her well, and it is a testament to the care and support of her family as main carers that kept Anna so well for so long. Anna had robust and holistic care from paediatric services which became more complicated as she transitioned into adult services.

Notable changes in provision impacted the whole family. Hospice care between paediatric and adult services is very different meaning reduced developmentally appropriate respite and not enough support for grieving families after losing a loved one. Anna's special needs school allowed a continuity in education until she was 19, but options for adults with complex and profound multiple disabilities are limited in our area and so more independent living for Anna wasn't felt to be an option.

Anna was eligible for children's and adults Continuing Healthcare (CHC) and her home care transition was managed very well with a continuous dedicated package of care including provision for private respite. Anna had contact with the learning disability liaison nurse at her local hospital who provided invaluable support during admissions as Anna transitioned into adult services including hospital passport updates. Anna had holistic, wrap around care from paediatric services and this was relatively well managed into adult care via rehabilitation medicine. However, coordination for this was heavily dependent on mum, and such young people without access to this level of advocacy would surely experience a much more disjointed process.

Anna was admitted to hospital following a severe and enduring seizure and was admitted to ITU. Her family were kept fully up to date on her condition and what her likely journey would be. As Anna deteriorated her family agreed palliative care was in her best interest, so active treatment was stopped the focus was moved to comfort and symptom control. Anna's family stayed by her side for end-of life care and Anna passed away peacefully with her family by her side.

Jake

Jake was a 48-year-old gentleman who lived in the family home with his parents. Jake was fully dependent on carers to meet his daily needs and his home was adapted for this purpose. Jake liked films, music, and computer games. He loved having baths and spending time with his family, going for long walks by the seaside or on the Sandringham Estate.

Jake was diagnosed with cancer the year before he died. A decision was made that the approach to his overall care should be palliative and focused on comfort and symptom control. He was referred to the community palliative care team and had a care plan formulation, anticipatory medication prescribed, as well as DNACPR and a ReSPECT document completed, which stated that he was for hospital admission only for reversable causes. Although the integrated palliative care team was involved, they had more of advisory role as it was decided that it was best that Jake's community learning disability nurse should continue to coordinate his end-of-life care. Jake was CHC eligible and although his package of care was well staffed and consistent there was limited case management from CHC which impacted the response to package issues.

Jake's palliative care was managed spectacularly with regular reviews, making sure all referrals and necessary interventions were completed, but also with support for Jake's family. Jake's palliative care status and what that involved, was hard for this family to understand. So, his community learning disability nurse arranged a joint visit with his consultant in palliative care medicine. This offered more clarity to his family and gave them a chance to have their questions answered. As the care coordinator, his nurse was able to arrange equipment, consumables, and training to manage Jake's secretions, using a new pathway designed to solve this exact issue. This learning from previous LeDeR reviews meant Jake was able to avoid an unnecessary hospital admission, despite an exacerbation of symptoms.

The multidisciplinary approach to Jake's care and excellent co-ordination through his community nurse was pivotal to the success of his hospital avoidance plan and end of life care at home. After a short deterioration Jake peacefully passed away during night with his family by his side.

James

James was an 81-year-old gentleman who had recently moved into his new care home, after his previous home closed. His new home was chosen as he had attended a day service on the same site, which meant that he was familiar with the environment and staff which eased his transition. James was described as a wonderful person with a very loving nature and a great sense of humour. He liked to have a strict routine and would join in with all the activities arranged at home including arts and crafts and baking. He also loved a disco and would join in with the dancing and liked to go out every day, especially on the bus.

James had regular annual health checks and all his vaccines, including for pneumonia. There was evidence of the GP recognising that due to James' limited communication, he was not always able to reliably express pain and discomfort in a way that was understood. During the pandemic they made home visits to review him and had a low threshold for referring to acute services. There was also evidence in all the records that professionals had assessed James' mental capacity to make decisions and there was noted good practice in capacity assessments and best interest meetings, including the use of an IMCA for decisions around life changing health interventions, such as investigations and treatment of a potential malignancy and end-of-life care decisions.

James had chronic kidney disease and went into renal failure, and a best interest meeting was arranged which agreed invasive intervention was not in his best interest moving forward. Unfortunately, James became unwell with a chest infection a month later and was admitted to hospital where he sadly passed away. James received excellent end-of-life care in hospital, and although his carers wanted to bring James home for this, he was too poorly.

If James' choices around end-of-life care had been discussed and a plan agreed before his discharge a month earlier, a hospital avoidance plan could have been created. The care home could have identified support to recognise that James was actively dying so that a decision could have been made to make him comfortable at home. He may then, have been able to die at home surrounded by the people who knew him.

Charlotte

Charlotte was a 69-year-old lady who lived independently and at the end of her life was receiving some home care support but was predominately supported by neighbours and friends. Charlotte had been married and widowed twice, she attended a day service two times per week and loved to watch TV, colour, and knit. Charlotte likely had a mild learning disability and the level of support she had from friends and family meant her needs were well met for a long time, and so Charlotte never had a formal diagnosis, which impacted her later care and support.

This was highlighted when she was unable to manage post operative wound care including dressings, ordering consumables, and understanding instructions and appointments. Charlotte could not read or write and had limited understanding of her now complex self-care needs. Yet there were difficulties arranging home visits with the district nurses as Charlotte wasn't "housebound".

Charlotte didn't have any learning disability annual health checks as she wasn't on the register however, she did have regular diabetes reviews, which noted abnormal blood tests and some weight loss. This led to timely further investigations which diagnosed her with pancreatic cancer. Similarly, although not alerted as having a learning disability, the consultant who diagnosed Charlotte with cancer identified the need for more support and referred her to the acute learning disability practitioner. They in turn continued to work with Charlotte as an outpatient and on her repeat admissions, giving her a known face to support her through a very difficult time.

Charlotte was admitted to hospital following a fall and quickly deteriorated. A decision involving the acute learning disability team was made for ward-based care and a palliative care referral was made. Charlotte sadly passed away in hospital.

12. Learning into Action

Once a review has been completed and learning has been identified, the team works with system partners including people with lived experience to make changes to services locally. Locally this is called Learning into Action and has the aim of preventing people dying from something that could have been treated and/or prevented and reducing health inequalities. Every review will generate areas of learning and most follow similar themes. Actions are agreed at LIAG and assigned a responsible person. They are recorded on an action log which is reviewed and updated every meeting. From last year's annual report, a lot of work has been done to respond to what we found including actions and work undertaken on behalf of the LIAG, and other works completed by the LeDeR team to further the aims of LeDeR within Norfolk and Waveney.

12.1 Learning into Action Group Work

Below is a selection of some of the work which has come out of LIAG in 2023/2024:

- Responding to reviews to make deaths relating to bladder cancer a local priority for focused reviews. We also had a meeting with the ICB cancer team, which was very successful and able to establish clear actions too look at this in more detail. Recurrent UTIs are not a red flag symptom or a referral criterion for the two-week cancer pathway. However, guidance suggests that a health professional might consider a non-urgent referral to urology should the recurrent symptoms occur. There is certainly an association between urinary tract infections and bladder cancer, but this is not unique to learning disabilities. However, this could be reflective of general issues in late diagnosis and diagnostic overshadowing. The meeting was able to agree some actions:
    1. The cancer team are due to update the bladder cancer referral form and will include recurrent urinary tract infections in this.
    2. The cancer team holds a monthly webinar for primary care. They will contact a urologist from the James Paget to discuss bladder cancer in those with a learning disability. Hopefully after July 2024.

3. The cancer team will add social care staff to their Talk Cancer Project, planned for the 2024/2025 financial year. They will include the insights gained from Opening Doors and create cascade training for social care staff working with people with a learning disability on common symptoms of cancer and how to spot them. This will include train the trainer options.

- We have started a new transition working group to look at some of the difficulties faced in transition to adult services and help services to work better together in planning and coordinating care across paediatric and adult services. We agreed to firstly look at improving the health services information on the Local Offer Website. Secondly, to formalise a process for monitoring and managing high risk transitions, modelled on the Dynamic Support Risk Register.
- We have focused on celebrating good practice over the last year, sending letters when possible, to highlight to teams where their practice has been exemplary and the impact this had. We have had much feedback noting how valuable and grateful teams are in receiving these letters.
- Work has started to support NCH&C and NSFT in collaborating to develop robust Dementia diagnosis and management pathways for people with a learning disability.
- NSFT have worked with acute teams to review the use of adapted assessment tools with all NSFT services and look for any training needs in scales such as MossPass. Also, to look at how joint assessments are managed with acute mental health and learning disability teams.
- We have been working with NSAB to look at improving MCA adherence across the region by collaborating on an education offer and work planning.
- Feeding back relevant case studies via the primary care newsletter to highlight areas of learning to GP practices.
- Work to clarify the responsibilities of mainstream and specialist learning disability community SALT teams to ensure people with mild learning disabilities, who could be supported by mainstream services, do not have delayed support due to refused referrals.
- Identifying areas for specialist training sessions for the Primary Care Learning Disability Leads Network including, the MCA, Care Education Treatment Reviews and the Dynamic Support Register, STOMP, maternity care for people with learning disabilities, social prescribing and cancer screening.
- Liaison with quality monitoring officers when specific care quality concerns are identified in specific care settings. Our team shares concerns and learning, which is used to guide how improvement plans are structured.

- Work between social care and community learning disability nursing colleagues to agree pathways so all people with a learning disability on a social care pathway that are presenting with end-of-life care needs will be referred to learning disability nursing. In addition, the palliative care team have been in contact with the local authority and been provided the contact details to all specialist residential and supported living units in Norfolk to ensure that providers have access to advice and support around providing end-of-life care to their residents.
- Supporting with the printing of 14+ birthday cards and pre-AHC questionnaires to support uptake and quality of annual health checks.

12.2 Other Work

- Using LeDeR learning to collaborate with the skills plan scoping phase underway for Norfolk and Suffolk.
- Supporting roll out of the Reasonable Adjustment Digital Flag for Learning Disability and Autism Services.
- Collaborating on a long-term care toolkit by the Learning Disability Quality Improvement Team by NCC which we informed using LeDeR learning.
- Contributing to the working group which is implementing the recommendations from the Clive Treacey Independent Review within our region.
- Work with public health commissioning to improve the accessibility of tier 2 weight management services.
- Supporting with Structured Judgement Reviews meetings to share learning from LeDeR where reviews are complete.
- Supporting a nationally chaired working group to co-author new NHS England Health Care Passport Guidance.
- We started a project to explore how our system could use the Health Equalities Framework (HEF) in learning disability services to implement an outcome-based way of working which better highlights vulnerabilities for people across their lives. A workshop was held to look at how this could be implemented in the system. Three achievable priorities were agreed as initial areas of action:
    1. The LeDeR team are introducing HEF to our learning disability LeDeR reviews. This is a novel way of using HEF and we hope HEF reports will help to identify where a person’s risks of health inequalities were and highlight gaps between inequality risk and service provision. This will better guide our learning into action work. Currently we cannot use HEF for Autism only reviews, as the tool has not been validated for use with autistic people.
    2. It has also been agreed the community learning disability nursing service will commence the rollout in the summer 2024. of completing HEF assessments upon allocation and discharge for all new episodes of care.

3. With some big commissioning projects on the cards over the next 18 months we hope to continue to show the benefit and value of HEF, with the potential for advocating for HEF to support outcome-based commissioning.

12.2.1 Training

Teaching has been a big part of our new work plan, spreading awareness and learning from LeDeR reviews, and changing practice by improving education. We have delivered training and education sessions to over 30 teams across health, social care and education over the last year. The aim of these sessions has been to share our learning and highlight and advocate for good practice. We have worked with colleagues at UEA to try novel approaches to imbed learning disability and autism education into health and social care courses by including LeDeR review case studies into academic work, including exam questions and assignment titles. In every session we requested feedback from participants to tell us how we did and suggest areas for improvement. We have highlighted some of the feedback below to demonstrate the impact.

	Score (*n*=112)				
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The session was informative	67%	32%	0%	0%	1%
The presentation was interesting	55%	38%	4%	2%	0%
The session was engaging	49%	38%	10%	2%	1%
The presenter was knowledgeable	88%	12%	0%	0%	0%
The content was relevent to your role	65%	32%	1%	1%	1%

12.3 Health Inequalities Team

The Health Improvement Team have continued with supporting people with learning disabilities and autism and GP practices, to promote health and wellbeing and increase the uptake and quality of annual health checks in 2023/2024.

- The team have worked with 21 surgeries who had a lower percentage of attendance for the annual health checks, this covered practices in Norwich, South Norfolk and the Waveney areas.
- Outreaching to patients (or their carers) who have not had their Annual Health Check for more than 12 months to support with attendance. Over 342 patients were identified from practices as requiring support. The team have made over 350 calls to patients and 120 home visits. The outcomes of these were vast but mainly included supporting a person to have their health check and onward referrals to social services or safeguarding.

- Provided training at 16 surgeries, including training for clinical and admin staff. The team hosted a session which was open to all admin staff across Norfolk and Waveney of which 60 people attended. Feedback following the training indicated that most attendees had an increase in confidence in arranging the annual health checks post attendance.
- Supporting surgeries with a learning disability register review to ensure its accuracy. We advised and supported practices to remove 67 patients from LD registers who did not have a learning disability.
- Supporting practices with implementing the guidance on reasonable adjustments and the digital flag.
- Along with colleagues from delegated commissioning team, we presented at the NCHC LD Community Team meetings to form closer working relationships and to share updates on the annual health checks.
- Engaging care and residential homes and day centres, directly and via quality teams to promote best practice and supporting residents with annual health checks.
- Promoting health and wellbeing at learning disability events, including those targeting ethnic minorities.
- Regularly attending meetings with the POCT (Point of Care Testing) project team to support the development and implementation of this project, of which data is currently being collected.
- Development of a venepuncture pathway is in process following feedback that this was required to support primary care.

12.4 Looking forward to 2024/2025

Some of the workstreams mentioned above will continue into next year and develop in response to any changes. However, from the reviews undertaken in 2023/2024, we know that we need to do more work in the following areas:

- Improving prevention and early recognition of respiratory illness.
- Strengthening practice in use of the MCA and decision making.
- Identifying where improvements are possible in the wider housing market to support vulnerable people.
- Improving the transition experience for young people with complex needs moving into adult services.
- Improving the use and quality of health action plans as part of a robust annual health check.
- Identifying lasting change which could improve cancer screening uptake.
- Continuing to raise awareness and knowledge of LeDeR in services supporting autistic people.
- Improving the early identification of end-of-life and planning of palliative care.
- Increasing the knowledge and understanding of ReSPECT and advocating for it to be used well, in its intended purpose as an emergency care planning tool.
- Improving service access to adapted talking therapies to reduce psychotropic medicines being offered as a front line treatment for mental health issues.

13. Feedback and Further Information

13.1 Working in Partnership

If you have a learning disability and/or autism, we want you to tell us what your own lived experience is like. We want you to tell us whether what we are doing is making any difference to your life. We want you to tell us if we are not doing enough to make change happen. We will find better ways of asking you, and better ways of listening to what you say. We will use the learning from the LeDeR programme and from your experiences to keep improving and make changes. Please contact us via these links:

nwicb.contactus@nhs.net Facebook Twitter

13.1.1 Knowledge NoW

A QR code has been shared below where providers can access resources to evidence-based health and wellbeing from our NHS website: https://nwknowledgenow.nhs.uk/

14. Conclusion

The team have experienced significant challenges over the last year due to an increase in workload. Despite the team having completed more reviews than last year and more detailed focused reviews, we are not completing reviews as quickly as we would like to. Our work continues to be incredibly well supported by health and social care providers across the ICS. We also continue to be indebted to the contribution from experts by experience and people with lived experience. Although our data collection has some limitations regarding generalisation, we do feel there have been some improvements in the quality of care and accessibility and effectiveness of services last year.

There has been an increased uptake in vaccinations and continued working and engagement from the ICB health improvement team in health promotion and preventative health interventions. This can also be seen in the increase in annual health checks and health action plans, something we will continue to promote and ensure all people with a learning disability from the age of 14 find a benefit to their long-term health and wellbeing. Quality remains an important part of this and there will remain continued work in this area. We also have seen improved use of reasonable adjustments to support people to access healthcare and improved evidence of use of the Mental Capacity Act. Yet, there remain areas for improvement in advocacy and listening to the voices of those we support.

Work continues to need improvement in preventing and treating respiratory infections and reducing respiratory related deaths, especially pneumonia. Better collaborative working and care planning is also required for those with chronic conditions and those at end-of-life. Application of Deprivation of Liberty Safeguards needs improvement as does documentation of decision making when this is being done on someone’s behalf. Less people are taking psychotropic medications but there remains room for improvement in adhering to STOMP principles. Quality oversight of residential services feels to be improving with a quicker response to concerns and good support resulting in lasting changes. However, service gaps remain for those living more independently, and vulnerabilities are not being identified early enough.

We have seen a continued increase to our notifications, we feel, due to our ongoing engagement and promotion of LeDeR within the system. We aim to better represent the experience of those with a sole diagnosis of Autism by continuing to outreach into services, raise awareness and support more referrals for those who have died. Lastly, it is important we conclude this annual report by again remembering each death which has been reported. Each referral was for a person from our community, with hopes, feelings and loved ones. It is vital therefore that we continue to use their stories and experiences to improve the service provision for all people with learning disabilities and/or autism across health and social care.