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

(LeDeR)

Norfolk and Waveney

Annual Report 2024-2025

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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 Programme Board

On behalf of the Integrated Care Board (ICB), I would like to welcome the publication of our eighth LeDeR Annual Report in Norfolk and Waveney. Firstly, I would like to acknowledge the skill and empathy required to ensure that the voices and experiences of the people reviewed are captured and that this learning is able to inform and shape the quality improvement work that will improve the care received by others. The local ICB LeDeR Team continues to provide expert review, analysis and recommendations, that are then taken forward into practical action by the ICB Learning Disability Health Improvement Team and wider system partners.

The ICB continues to be grateful for the engagement of families, carers, and friends. The importance of ensuring that each review reflects the individual at the centre of it; how they experienced the world and what they meant to those who cared for them, is particularly powerful in the report’s section on lived experiences, which can be found on pages 48-55. We would also like to recognise and thank staff from across the health and social care system for providing care records and other information required to complete each review to a robust and high standard, as well as the insights shared from their professional practice and experience, to help create meaningful and impactful actions. Local support for the programme continues to be outstanding. We are seeing an increase in referrals relating to Autistic people and this reflects better understanding of opportunities for learning and service improvement, specifically, around autism support needs and gaps in health equality.

Sadly, people living with learning disabilities and/or Autistic people continue to have a shorter average 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, throughout the life span. The data presented in this report shows that each year we are reviewing more deaths at an age of 65 years and older and while the data sample is much too small to comment on the overall mortality rate, it is heartening to see evidence of people living with learning disabilities and/or Autistic people living into their older age. We can also see that the grading of people’s quality of care continues to improve and there is a strong theme around prevention running through the report and into the actions and recommendations, aligning with the fundamental national aspirations of the 10 Year Health Plan for England. Locally, this can be evidenced by our continued work to improve vaccination uptake and make cancer screening and earlier diagnosis more personalised and more accessible.

From notifications, the leading theme in cause of death in Norfolk and Waveney continues to be respiratory illness. There is evidence throughout the report of the importance of making access to preventative treatment, including but not limited to immunisation, more equitable. While there is still work to do in this area, we note that of the reviewed people, there was an increase in both flu and pneumococcal vaccine uptake across those people eligible, over the year. Next year’s report will also include recording of the new Respiratory Syncytial Virus vaccine.

The reviews across the last year illustrate how early planning, collaborative working and good practice around reasonable adjustments has been shown to manage complex health and social care issues, which can often intersect. The benefit of Annual Health Checks is also a feature, with opportunities for professionals to identify unmet and unrecognised health conditions, leading to earlier actions to begin treatment and improve outcomes. This can be especially impactful when combined with long term condition reviews, to provide a ‘whole person’ approach that joins up elements of care and treatment. Our system has seen a consistent improvement in Annual Health Check (AHC) uptake; exceeding the national target of 75% for the first time this year.

The ICB continues to be committed to ensuring that people living with learning disabilities and/or Autistic people are supported to live healthy and happy lives. I support the improvement priorities identified across the coming year and look forward to the next steps of this quality improvement journey into the year ahead and beyond.

Rachel Clarke: Co-ordinator for Family Voice Norfolk
My name is Rachel Clarke, and 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 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.

I have been attending the LeDeR reviews on behalf of FVN for over three years now. I bring a parent/carer perspective to the meetings as I am mum to an adult son in his twenties who, through complications of extreme prematurity, has required constant and consistent care since birth. He is autistic, has a learning disability, ADHD and mental health difficulties and is currently fully supported at home. Within our home, we work every day towards him being able to be more independent and feel sure he will achieve greater independence of us, one step at a time, in his way and in his time.

Independence looks very different for each of our unique children and young people. One thing, however, is certain. That we, and he, need to consider his future eventually without us, and what that might look like. As a young man, he is able to look at and research topics. I cannot express how I felt the day he came to me and said he’d read that ‘people like me have a much shorter life expectancy mum’. Wouldn’t it be wonderful for that not to be the case?

The LeDeR work and reviews are about people. People who have been someone's son, daughter, parent, partner or sibling. Each review is treated with great care and a picture is built of that person's experience. We learn of examples of excellent practice, of occasions of care that goes 'above and beyond', and these are rightly celebrated. We learn of instances where there have been shortcomings, missed signs, a lack of joined-up of services and missed communications and opportunities.

As a parent, I am grateful to all those who allow us to follow each person's experience of care and support, to take learning from it and to work towards improvements for quality of care. 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. It is a privilege to be involved in LeDeR and the learning that comes from it, working towards better care futures and experiences for those who have a learning disability and/or autistic people.

Contents

1. Acknowledgments

Not to repeat previous years reports but it remains our first responsibility to acknowledge, remember and thank, all the people who have contributed to LeDeR by sharing their stories with us, following their death. The team never underestimates the privilege we have in exploring people's 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.

Again, 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. Special thanks go to our partners with lived experience for their guidance, support and challenge.

2. Executive Summary

Welcome to the NWICB LeDeR report. This is the eighth annual report in Norfolk and Waveney on the reviews of the lives and deaths of people with a learning disability and/or autistic people since the inception of the LeDeR programme in England in 2017. It is the responsibility of all ICBS 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. Any analysis primarily describes the current situation in Norfolk and Waveney. 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 2024 to 31st March 2025. The deaths reviewed cover a longer period with the earliest having occurred in 2021. This is due to death reporting delays but also delays in the review completion. Summary findings from the Norfolk and Waveney reviews in 2024/2025 can be seen on the next page:

Reviews demonstrated an increase in Quality of Care, but a smaller number of reviews than last year graded the Effectiveness and Availability of Services as being satisfactory or above

Pneumonia is the most common, and aspiration pneumonia the second most common leading cause of death.

Classifications in the first part of death certificates have been worse this year which can lead to post-mortem diagnostic overshadowing.

Combined aspiration and other pneumonias accounted for 32% of all leading causes of death in our completed 2024/2025 reviews, which is slightly less than last year.

We continue to see more deaths at a higher age in both reviews and notifications, with 49% of reviews for those aged 65 and over. This has increased for the last two years.

More people are attending their annual health check, but we still see an inequality in provision with a 15% difference between the best and worst performing localities.

The most common single comorbidity is still Epilepsy, then Hypertension, then Dementia.

Fewer people died in hospital and more people died at their usual residence.

Cardiovascular Conditions was the highest grouping of co-morbidities, with Hypertension being the biggest contributor to this.

The median age of death for all completed reviews in 2024/2025 was 63 years old, which is an increase of 1 year, this has increased for the last two years.

44% of reviews had a cause of death which could be considered avoidable. This represents a reduction of 10% on last year.

All cancer screening has seen an increased attendance percentage wise

Pneumonia vaccine uptake has increased again this year. Influenza uptake remains high, and we know we need to improve Shingles uptake.

This year 59% of reviews had psychotropics prescribed, an increase of 20%. Some of this may be explained by our increased Autism only reviews.

More reviews have evidence of MCA assessments being completed and less evidence of variable compliance in completion of MCAs.

A lower percentage of people who were prescribed psychotropics, had them for a mental health condition or behavioural management and fewer of these had been on psychotropics for over 5 years

Reviewers have seen a marked increase in the quality of ReSPECT forms, so they better reflect the person they are about.

The LeDeR team are very busy and are not completing review as quickly as we would like and we have again received more notifications than last year.

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 autistic people aged eighteen years and over. Latest figures available estimate there are approximately 1.3 million people (950,000 adults and 350,000 children) living in England, known to have a learning disability. This is equivalent to 2.16% of the adult population in the UK [1]. As at the end of March 2024, 6,965 people were registered with GP practices as having learning disability in Norfolk and Waveney, out of a total population estimate of 1,032,472[2]. Our area has one of the highest percentage learning disability representations in England[3].

The LeDeR programme[4] 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. A full explanation of the review process including national priorities for a focused review can be found in the LeDeR policy[5].

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 autistic people. 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 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 autistic people at https://leder.nhs.uk/report

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[1] https://www.norfolkinsight.org.uk/wp-content/uploads/2025/01/Adults_with_Learning_Disabilities_Briefing.pdf
[2] https://www.norfolkinsight.org.uk/
[3] Quality Assessment Framework 2021/2022
[4] https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf
[5] Section 3/page 12 of https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf

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. Despite challenges in delivering the reviews in a timely manner, quality and safety remain team's priority. Delivering LeDeR reviews within the nationally targeted timeframe has been incredibly difficult. A historical backlog due to team capacity and an ever-increasing number of notifications has meant the team is consistently not achieving its target of review completion within 6 months of notification. Our drop in performance means we risk losing the opportunity to learn lessons and improve services when things go wrong and rely increasingly on retrospective reviews. Ultimately impacting our ability to deliver service improvement and improved health outcomes for people with a learning disability and autistic people.

Our team has responded to this and changed our ways of working, where we can, to try and reduce the time it takes from review notification to allocation to a reviewer. This is largely where the delay is, as looking at our actual performance, our team are overwhelmingly completing reviews, following allocation, within three months. We have changed some of our admin processes for example contacting families earlier to invite them to be part of a review and reducing the size of the reviewers note bundles by removing miscellaneous information. Our reviewers are taking a broader "theme" approach to initial reviews, and we are making better use of their time by reducing expectations to attend sign off panels.

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 Integrated Care Board's Learning Disability and Autism Programme Board and Learning from Death Forum. To try and improve performance and reduce the time from notification to review sign off, our team has streamlined some of the review sign of processes over the past year.

5.1 Initial reviews

Initial reviews are now discussed between the reviewer, the Senior Clinical Lead for Learning Disabilities and Autism Quality Improvement and the Local Area Contact (LAC). This meeting allows scrutiny over the review and its quality and to ascertain if the recommendations address the identified learning. If appropriate 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 month.
- Norfolk Safeguarding Adults Board – Every 12 months.
- Social Care Quality Improvement Programme – Every 12 months.
- Norfolk And Waveney Integrated Care Partnership – Every 12 months.

6. Performance

The team works to achieve 100% of reviews completed within 6 months of notification. At the end of Quarter 4 (Q4) the team has completed 14% (9 out of 63 reviews) within 6 months of notification in the 2024/2025 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.

Last year the ICB signed off 56 reviews and in 2024/2025 the team have completed 63 reviews, an increase of 13%. We carried forward 51 reviews from the 2023/2024 review period and this year we are carrying over 79 reviews into 2025/2026, so 35% more than last year. The team is also tasked by NHS England to convert a minimum of 35% of reviews from initial too focused. This year the team has again exceeded this target and achieved 37% of reviews being focused.

7. Overview of Notifications

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 may be higher. Our team have received 107 notifications in the 2024/2025 period, of which 98 are known at the time of writing to be in scope for review. Notifications have increased year on year with an increase of 32% on last year. 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 2024/2025 was 19 years of age and the oldest was 91 years. Most of our referrals were for people between 46 and 64 years old which has changed from last year as shown in Figure 2. This year's data shows a decrease in the median age at death of notifications from 63 years to 61 years of age. This may reflect the increased number of autism referrals we received in 2024/2025. The ages of the autism only referrals mostly fell within the 46-64 grouping and the overall median age of death of 58 years old. 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.[6]

7.2 Gender

Overall, the number of notifications for men was higher at 63%, whereas last year the representation was very similar across genders. See Figure 3.

7.3 Diagnosis

The majority of our referrals were for those with a diagnosis of a learning disability (88%). A small number had a diagnosis of both a learning disability and autism (5%). The team received 8 notifications for people with a sole autism diagnosis, compared to last year when we received 6. The team has reviewed reported deaths for people with a diagnosis of autism using GP records, which indicates there is a good awareness of LeDeR within autism and mainstream services and most deaths are being referred to our service for review.

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

7.4 Place of Death

Place of death is not a mandatory question for referral completion. At the time of writing, 96 of the notifications were both in scope and had 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 2024/2025 happened in hospital, 61% (*n*=60) overall, and 32% (*n*=31) occurred in the person's usual residence. 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, but also previous years. Although it has lessened, we do still receive referrals from previous reporting periods and previous year's figures have been updated to reflect this. Again, it is important to note LeDeR reporting is not statutory and so there are likely gaps in this data. Also, our notifications have consistently increased year on year which may explain increases in deaths in a particular month.

7.6 Ethnicity

Of the notifications from 2024/2025 where the ethnicity was disclosed, 99% (*n*=106) 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, influenza and respiratory failure leading across the board. This profile is different to the general population where the top three COD in 2023, (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[7]. Again, a COD is not a mandatory question for referral completion. As such, at the time of writing, only 86 of the notifications were in scope or 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.

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[7] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2023#leading-causes-of-death

7.8 Area of Deprivation

Indices of Multiple Deprivation (IMD) is the official measure of relative deprivation for postcodes in England. The IMD ranks every postcode from one (most deprived area) to 10 (least deprived). Our notification IMD again shows a shared mode score of 4 and 5 this year. The overall breakdown shows more people with a learning disability and/or autistic people living in areas with an IMD score of 5 or less. This is still higher than the general population where 2019 data (latest available) shows 52% in Norfolk live in an area with an IMD score of 5 or less[8]. For the 98 in scope notifications, the difference between the top and bottom 50% is narrower than our completed reviews for 2024/2025.

IMD Score	Number of Notifications	Percentage	Number of Notifications	Percentage
1	7	7%	57	58%
2	10	10%		
3	12	12%		
4	14	14%		
5	14	14%		
6	13	13%	41	42%
7	13	13%		
8	12	12%		
9	2	2%		
10	1	1%		

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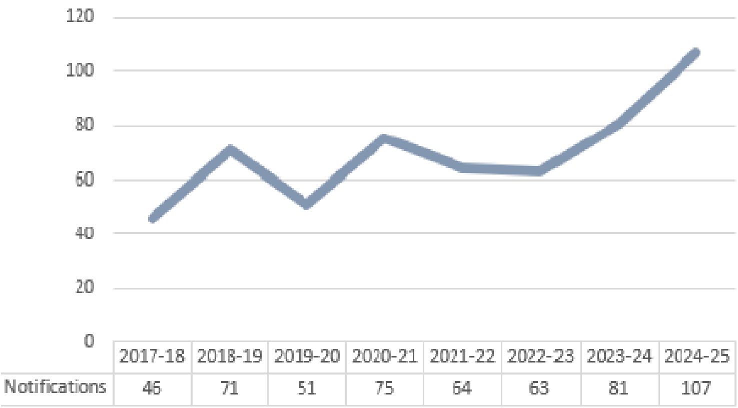
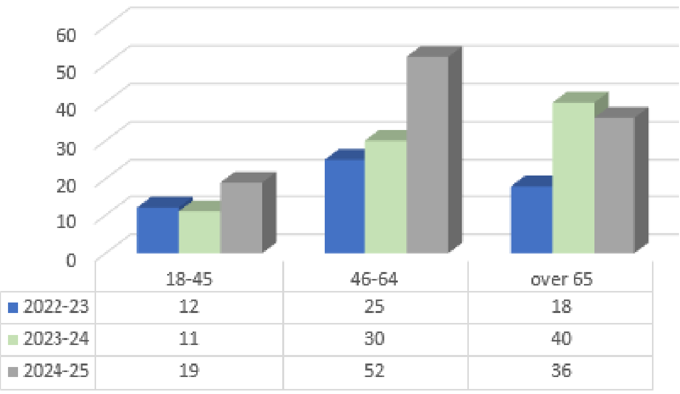
[8] https://www.norfolkinsight.org.uk/deprivation/reports/#/view-report/8b97d75c317745b3a6016fc0788469d1/E10000020/G3

1 Number of Notifications



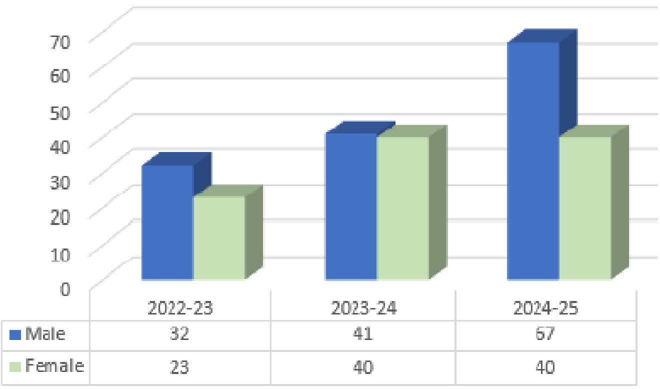
	2017-18	2018-19	2019-20	2020-21	2021-22	2022-23	2023-24	2024-25
Notifications	46	71	51	75	64	63	81	107

2 Age at Death - Notifications



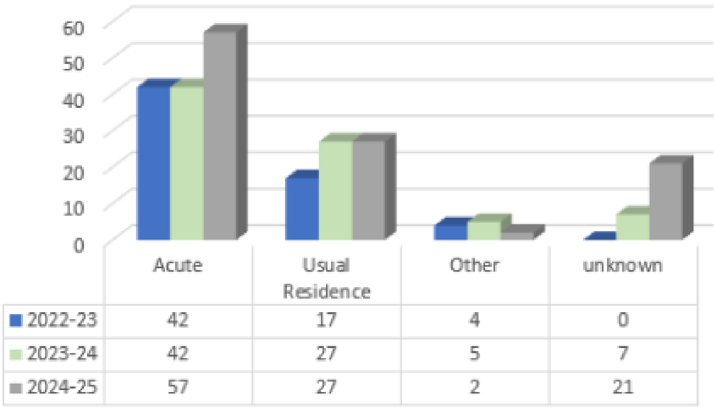
	18-45	46-64	over 65
2022-23	12	25	18
2023-24	11	30	40
2024-25	19	52	36

3 Gender - Notifications



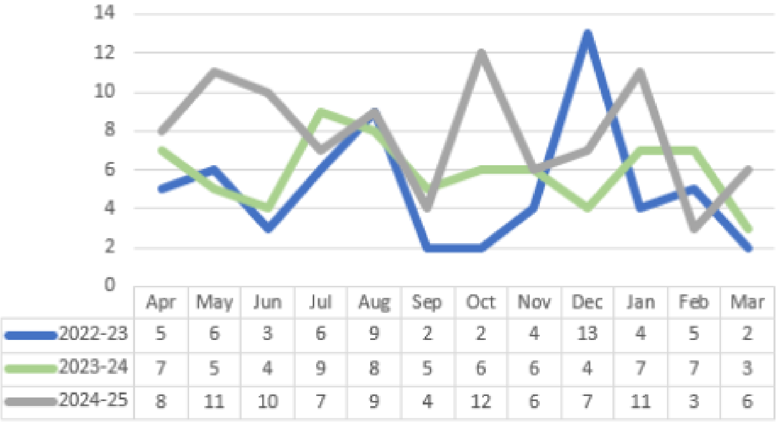
	2022-23	2023-24	2024-25
Male	32	41	67
Female	23	40	40

4 Place of Death - Notifications



	Acute	Usual Residence	Other	unknown
2022-23	42	17	4	0
2023-24	42	27	5	7
2024-25	57	27	2	21

5 Death by Month - Notifications



	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
2024-25	8	11	10	7	9	4	12	6	7	11	3	6

8. Overview of Completed Reviews

The LeDeR review performance report as at the end of March 2025 shows that 82% (*n*=456) of 556 reviews received since 2017 have been completed by the 2024/2025 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
2024-25	107	63	79
Total	**556**	**456**	

In 2024/2025 63 initial and focused reviews have been signed off as complete. The team have completed more reviews than previous years but also carrying over more reviews this year demonstrating the increased workload of the team. To look at breakdowns in 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 and Availability and Effectiveness of Services 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 63 reviews completed in 2024/2025, 40 (63%) were initial reviews.

8.2 Focused Reviews

Of the 63 reviews completed in 2024/2025, 23 (37%) were focused. The singular biggest reason for a focused review was due to autism only as this is a national priority. Locally, 22% were converted to focused due to care quality concerns and 22% 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, history of being held under a section of the mental health act and local priorities.

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. Grading is based on the information the reviewer has gathered and presented at panel. Of the 23 completed focused reviews from 2024/2025, a higher number of the reviews than last year graded the Quality of Care as being satisfactory or above (*n*=10). Likewise improving, a smaller percentage (57%) of reviews demonstrated care which fell short of expected good practice. There were 5 reviews where this was judged to have impacted the person's wellbeing. At 22%, this again is an improvement on last year. The below table shows the grading of care for completed reviews for 2024/2025.

Rating	Standard	Number	Percentage
6	This was excellent care (it exceeded current good practice).	0	0%
5	This was good care (it met current good practice in all areas).	5	22%
4	This was satisfactory care (it fell short of expected good practice in some areas, but this did not significantly impact on the person's wellbeing).	5	22%
3	Care fell short of expected good practice but did not contribute to the cause of death.	8	35%
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.	4	17%
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.	1	4%

Of the 23 completed focused reviews from 2024/2025, a smaller number of the reviews than last year graded the Effectiveness and Availability of Services as being satisfactory or above (*n*=8). Likewise, 65% fell short of expected good practice which is a slight increase. However, 7 reviews were judged to have impacted the person's wellbeing. At 30%, this is an improvement on last year. The below table shows the grading of Availability and Effectiveness of Services for completed reviews for 2024/2025.

Rating	Standard	Number	Percentage
6	This was excellent Service Effectiveness and Availability (it exceeded current good practice).	0	0%
5	This was good Service Effectiveness and Availability (it met current good practice in all areas).	4	17%
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).	4	17%
3	Service Effectiveness and Availability fell short of expected good practice but did not contribute to the cause of death.	8	35%

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	27%
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.	1	4%

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. We continue to see more deaths at a higher age in both reviews and notifications. The median age of death for all reviews in 2024/2025 was 63 years old, which is an increase of 1 years from last year’s annual report. This is slightly higher than the median age of death from our notification data which stands at 61 years of age for 2024/2025. Our median age of death for the eight autism only reviews was 54 years of age. The latest national data from 2022 shows 85% of people in the general population died at age 65 years and over[9], in Norfolk and Waveney 49% of reviews were for those aged 65 and over. This an increase of 5% from 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
2021-22	<5	10	27	23
2022-23	7	12	25	19
2023-24		11	21	24
2024-25		9	23	31
Total		**93**	**175**	**201**

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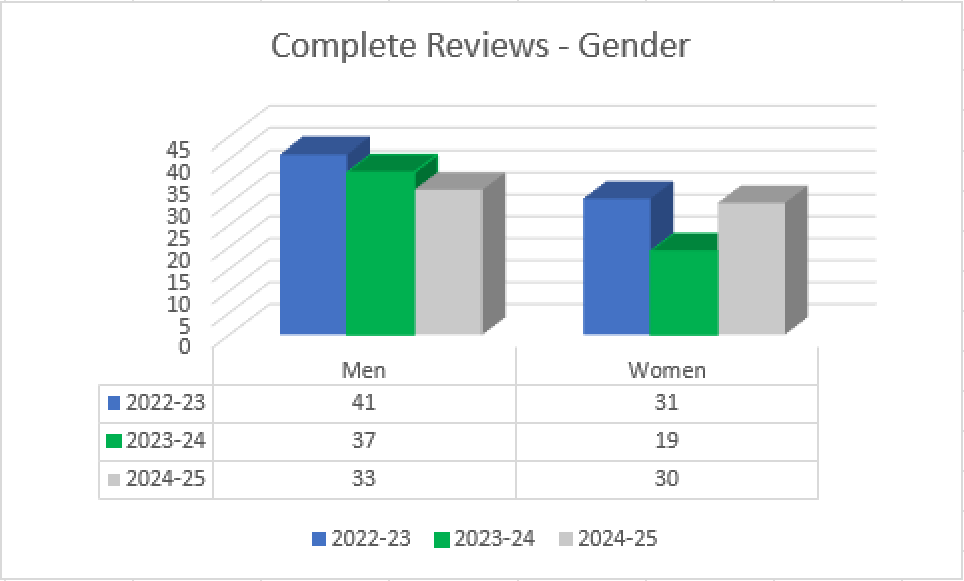
[9] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredinenglandandwalesseriesdrreferencetables

8.3.2 Gender

Of the 40 initial reviews we had slightly more men (58%) reviewed than women (43%). Of the 23 focused reviews, most were for women (57%), with 43% for men. Last year there were significantly more men having a focused review. Overall, we completed 33 (52%) reviews for men and 30 (48%) reviews for women. Most of the autism only reviews were for women.



	Men	Women
🟦 2022-23	41	31
🟩 2023-24	37	19
⬜ 2024-25	33	30

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 1 review where the person was not white British (1%). 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 2024/2025, 52 (82%) of reviews had a learning disability diagnosis which is a similar representation to last year. Fewer people, (5%) had learning disability and autism diagnosis. All autism only deaths were converted to focused as per the national priorities. We completed 8 reviews for people with a sole diagnosis of autism, an increase from last year.

8.3.5 Level of Learning Disability Severity

Across all reviews we had very similar numbers of men and women with a mild and moderate learning disability but notably more men reviewed had a severe learning disability than women, this year. Most initial reviews (45%) were for people with a moderate learning disability, followed by mild (35%) and then severe (20%). Of the 24 focused reviews with a learning disability, the representation was the same for those with a mild and moderate learning disability (29%) followed by profound. Last year we had more reviews for people with a mild learning disability, whereas this year we had more reviews for people with a moderate learning disability.

Level of Learning Disability	Number	Percentage (*n*=55)
Mild	21	38%
Moderate	25	45%
Severe	8	15%
Profound	<5	xx%

8.3.6 Areas of Deprivation

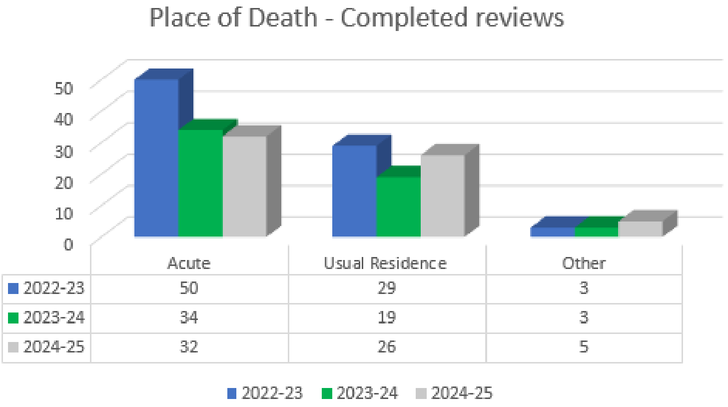
Our local data collection methods allow us to review the Indices of Multiple Deprivation (IMD) for all the completed reviews. As seen in the below table, most people reviewed lived in an area with an IMD score of 5 which is lower than last year. Overall, as with our notifications for 2024/2025, most 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. Of our reviews, 18% lived in areas with the lowest IMD scores of 1 or 2 and only 5% in areas with a the highest IMD scores of 9 or 10

IMD Score	Number of Completed Reviews	Percentage	Number of Notifications	Percentage
1	5	8%	39	62%
2	6	10%		
3	5	8%		
4	7	11%		

5	16	25%		
6	9	14%	24	38%
7	8	13%		
8	4	6%		
9	2	3%		
10	1	2%		

8.3.7 Place of Death

From our initial reviews, most people died in hospital (50%), followed by the persons usual residence, whether that be a private home, care home or supported living (45%). Our focused reviews reflect the same, with 52% dying in the acute setting. The same number of focused reviews died in combined residential services including care homes and supported living (35%). Overall, most (51%) people died in the acute setting, but at a reduced percentage to last year, and 41% died at their usual residence, which is an increased percentage to last year.



Learning identified from the reviewers:
The majority of people reviewed died in the acute setting. However, there were several cases where end-of-life was managed in the person’s preferred place (i.e. home, care home or supported living) with appropriate support for staff, admission avoidance plans in place and support from the GP, community nursing and palliative care teams. Yet, although in some cases reviewers saw there were

advance care plans in place, there was often no clear care plan for symptom management. As such, reviewers repeatedly saw care homes sending patients to hospital if they felt they did not know what to do to support the person adequately towards the end-of-life.

Discharging to a suitable home environment, where residential care is needed, remains challenging for hospital colleagues. Especially where someone's needs have changed, and they present with more complex needs. There are also clear opportunities for better planning and preparation when someone is being discharged on an end-of-life pathway, ensuring appropriate medications and referrals are in place and care providers are prepared and supported to deliver end-of-life care at home.

8.3.8 Accommodation

Most people who had an initial review lived in a care or nursing home (42%), with 30% living independently or in the family home and slightly less in supported living (28%). Most people who had a focused review lived independently or in the family home (48%) with 30% living in a care or nursing home and 22% living in supported living. Overall, 63% (*n*=40) of people lived in residential services and 37% (*n*=23) lived independently or in the family home.

Learning identified from the reviewers:
The majority of people reviewed lived in some element of residential care with the majority being where 24-hour care is provided. There are noted and ongoing barriers to accessing appropriate care provision due to challenges in the care market. This has been especially seen in home provision for individuals with profound learning disability and more complex health needs. Due to a lack of suitable accommodation and because of home closures, reviewers have seen in multiple reviews where individuals were placed into unsuitable accommodation or having to remain in a temporary placement for long periods while a more suitable placement was found. For example, one review highlighted where a person required a hospital bed for 6 weeks post being medically fit for discharge due to delays in sourcing equipment, training and transport which had a significant impact on their wellbeing.

On the reverse however it is important that we reduce the number of unnecessary moves for a person. Reviewers understand that a timely discharge from hospital is important but continue to see in reviews where a Discharge 2 Assess (D2A) bed was sourced, 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. Our assessments of people and their needs must be thorough and up-to-date as we have seen restricted housing options due to poor support for behaviour that professionals deem challenging.

Reviewers also often see a person moving into a care home from supported living due to a deterioration in their health, and then dying a short time after in an unfamiliar environment where increased care in the home could have been better resourced and considered. Excellent care was noted from some supported living providers in going the extra mile supporting individuals in their care when their needs have changed, to enable them to remain at home for end-of-life care. Accommodation and care provision also need to be foundational considerations for transitional care. Mapping of the transition journey to take into account of the different ages (16 - 20) at which a person may move between services is important, while also planning for the crisis or "What if" situation; for example, in the future for when parents age or become unwell.

There is also room for improved knowledge, skill and experience within supported living to allow aging, deteriorating or end-of-life residents to live in their home as long as possible. Many reviews have noted where people have been supported to move to a more independent living or foster family under the shared lives scheme, this has proven to be incredibly empowering and life changing. For those living with parents and/or family carers, earlier planning for future accommodation would benefit from conversations and planning happening before a family reach a crisis point. Also, for those living more independently there is also a lack of respite provision for complex health needs for individuals with a learning disability putting increasing pressure on carers. Respite is important for the wellbeing of people and their families and this needs to be developmentally appropriate and engaging.

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 63 completed reviews demonstrate most 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 30% (*n*=19) of reviews. Hypertension also remains one of the most common with a similar prevalence to Dementia. Cardiovascular Conditions 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	19	30%
Hypertension	15	24%
Dementia	15	24%
Hypothyroidism	10	16%
Type 2 Diabetes	9	14%
Asthma	8	13%
Constipation	8	13%
Depressive Disorder	8	13%
Dysphagia	8	13%
Chronic Kidney Disease	7	11%
Sleep Apnoea	6	10%
Stroke	6	10%

Group Comorbidity	Frequency	Percentage
Cardiovascular Conditions	41	65%
Neurodegenerative Conditions	39	62%
Endocrine Conditions	30	48%
Mental Health Conditions	26	41%
Genitourinary Conditions	24	38%
Gastrointestinal Conditions	17	27%
Musculoskeletal Conditions	15	24%
Respiratory Conditions	14	22%
Developmental Disability	12	19%
Eating & Drinking Conditions	11	17%

Learning identified from the reviewers:
Reviewers have seen where obesity has been left repeatedly unaddressed, for example in one case where a person had an extremely high BMI leading to type 2 diabetes and end stage renal failure, where there was no referral for dietician support. There have been multiple incidences of poorly managed chronic conditions, including diabetes which has resulted in retinopathy. Often however once a person is diagnosed, especially where there is an annual health check, we see good regular reviews including blood monitoring and medication reviews. Learning disability psychiatry respond well to managing serious mental illness and we have also seen appropriate consultation with secondary services and positive onward referrals to the community learning disability teams when needed.

Where autism diagnosis waiting lists are long, management of mental health can be variable. Yet reviews have shown where someone had a person-centred approach after diagnosis, which met their autistic needs, this led to a period of stability in their mental health condition. Problems with ongoing care and support with secondary services are notably present where is no diagnosis of a mental health condition and poor application of reasonable adjustments which can present barriers to service engagement, yet where needs are identified good support is observed.

Collaborative working and good application of reasonable adjustments has been shown to manage difficult health and social care issues which intersect. In a review we saw bespoke support from drug and alcohol services including continuity of keyworker and home visits to support someone’s recovery while working with colleagues from other services to help them move into secure and safe housing while avoiding the need for hospital admissions.

8.3.10 Causes of Death

As part of our post review process, we collate causes of death (COD) 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

The most common leading causes of death for all of the 63 reviews completed in 2024/2025 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 pneumonia is the most common, and aspiration pneumonia the second most common, leading cause of death in Norfolk and Waveney. Combined aspiration and other pneumonias accounted for 32% of all leading causes of death in the 63 reviews completed in 2024/2025, which is slightly less than last year. Cancer remains the third most common leading cause of death, with incidences of bowel, breast and other cancers.

Leading Cause of Death	Number	Percentage
Pneumonia	11	17%
Aspiration Pneumonia	9	14%
Cancer	8	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	27	43%
Neoplasms (Cancers)	8	13%
Diseases of the Circulatory System	6	10%
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	5	8%

8.3.12 Underlying Causes of Death

The two most common underlying causes of death for all the reviews completed in 2024/2025 were pneumonia at 16% (*n*=9) and then cancer at 13% (*n*=8). 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 to protect anonymity only those with above 5 are listed. This year we only had the top two underlying causes of death with more than 5 incidences. Below are the underlying causes of death by ICD-10 chapter.

Underlying Cause of Death Chapter	Number	Percentage
Diseases of the Respiratory System	15	24%
Neoplasms (Cancers)	8	13%
Diseases of the Circulatory System	8	13%
Diseases of the nervous system	5	8%

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[10] 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 47 Norfolk and Waveney reviews included in this definition, 28 were coded as avoidable, this equates to 44% of the total reviews. This represents a reduction of

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

10% on last year, and 2 fewer avoidable deaths. Yet, this still far exceeds the avoidable death rate of the general population of 22%[11]. In our autism only reviews, six out of eight reviews could be considered avoidable with most of these being preventable.

Avoidable Causes of Death	Number	Percentage
Treatable	17	24%
Preventable	9	14%
Treatable and Preventable	2	3%

Appropriate classifications for causes of death are vital to ensuring these figures are accurate. ONS Guidance for the completion of MCCD[12] 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 worse this year with COD such as “Learning Disability” being seen more. 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 “old age” which should only be used very limited circumstances.

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[13]. 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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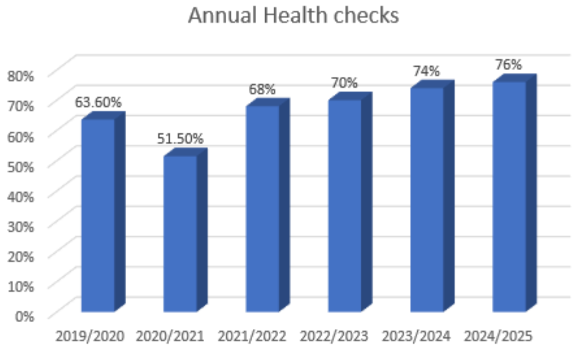
[11] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/bulletins/avoidablemortalityinenglandandwales/2023

[12] https://www.gov.uk/government/publications/medical-certificate-of-cause-of-death-mccd-guidance-for-medical-practitioners/guidance-for-medical-practitioners-completing-medical-certificates-of-cause-of-death-in-england-and-wales

[13] https://www.ndti.org.uk/assets/files/RH_Health_Checks_Guide.pdf

Performance for 2024/2025 across the different localities in Norfolk and Waveney, is measured and can be seen in the figure below. Notably there is nearly a 15% difference between the best and worst performing areas, which is a slight increase from last year and 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. Barring 2020/2021 where COVID-19 was felt to have impacted completion, our system has seen a consistent improvement in numbers culminating in exceeding the national target of 75% for the first time this year.



Locality	# on Learning Disability Register (March 2025)	# of Declines	# of AHC Delivered+	% of AHC delivered*
Great Yarmouth and Waveney	1817	157	1578	79.9%
North Norfolk	1196	98	1063	82.1%
Norwich	1547	79	1228	75.5%
South Norfolk	1408	101	1151	76.3%
West Norfolk	997	115	748	67.3%
Total	**6965**	**550**	**5768**	**76.8%**

+Using manual adjustments & automatic reports via CQRS National (April 2024 – March 2025)
**(AHC delivered divided by Declines + Learning Disability Register Total)*

Comparing this with the LeDeR reviews, out of the 55 completed for those who were eligible for regular AHCs, 80% (*n*=44) had been offered an AHC in the 12 months before they died, which is a decrease on last year. Our post review data collection is also able to tell us that 75% (*n*=41) attended their AHC, in the last 12 months before they died, which is an increase on last year.

Learning identified from the reviewers:
AHCs are a foundation of preventative care for people with a learning disability, and an essential part of managing co-morbidities and reducing mortality. Most AHCs are completed using a preset template on GP systems, this ensures some consistency and its helpful when checks are completed with some detail. However, sometimes AHC appear to be “tick box exercises” which do not reflect a person’s individual circumstances. Reviews have highlighted the support provided by the ICB Health Inequalities Team in outreaching to individuals who are not attending their AHC and liaising with GP and other professionals to increase uptake.

We see good practice when AHCs are combined with long term condition reviews and a whole person approach. We also see good practice where blood tests and other investigations are arranged before the AHC so these can be addressed in the appointment as opposed to needing to arrange a follow up. We have started to see the limited use of pre-AHC questionnaires being used which is extremely good practice and we hope to see more over the next year. Currently these are not standardised, and reviewers have seen an easy read version which is user friendly and accessible; and another version which asks a lot of questions and often uses medical jargon language.

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. 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. 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

Of the 41 completed reviews where there was an AHC in the last year of their life, 28 (68%) mentioned a HAP was in place which is a small increase on last year. The information from data collected by the Primary Care Team for HAP completion as part of an AHC in 2024/2025 is very different as seen in the table below. This year's primary care figure is 78%, which is a small increase on last year but a continuing improvement on 2021/2022, where only 56% had a HAP.

Locality	# on Learning Disability Register	# of HAP completed	Percentage*
Great Yarmouth and Waveney	1,817	1,423	78%
North Norfolk	1,172	1,010	86%
Norwich	1,547	1,204	78%
South Norfolk	1,408	1,115	79%
West Norfolk	997	714	71%
Total	**6,965**	**5,466**	**78%**

Learning identified from the reviewers:
Although many annual health checks mention a health action plan has been created, reviewers have seen very few in the notes for any reviews. Where they have been present, they are very basic but overall, 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 5 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 17 reviews with these eligibility criteria, only 2 had evidence of a AAA screening being completed, despite 14 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. Of the 15 reviews with these eligibility criteria, only 2 (13%) had evidence of attending cervical screening, despite 7 having had an AHC in their last year of life. This is an increase of 13% on last year.

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. Of the 12 reviews with these eligibility criteria, 7 (58%) had evidence of attending breast screening with 8 having had an AHC in their last year of life. This is an increase of 18% on last year.

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 21 reviews with these eligibility criteria, 16 (76%) had evidence of having their bowel screening with 15 having had an AHC in their last year of life. This is an increase of 18% on last year.

Learning identified from the reviewers:
Cervical screening uptake overall remains low, and reviewers often see it classed as declined by patient, even when they may lack capacity. Reviewers do not usually see evidence of reasonable adjustments in undertaking the capacity assessments and if best interest is being considered this is not documented or evidenced. Furthermore, reviewers have seen some individuals not invited at all as they appear in the system as “opted out”, with no recording of how this decision has been established and how the mental capacity act has been used to establish this.

Reviewers found a better uptake of breast screening however have also seen challenges in accessing mammography for those using wheelchairs or who have atypical posture. When mammography is not possible, education for people and their carers has been provided on breast examination which is good.

Reviewers still see bowel screening used as an investigatory tool in response to symptoms, which again may explain why the screening rates are comparatively higher to other cancers. Reviewers have seen evidence of good follow up from some GP practices to people not responding to bowel screening invites, explaining what bowel screening is and why it is important to complete it. Use of the reasonable adjustment digital flag and recording of needs by SNOMED code (a standardised language for digital patient notes) may be beneficial in supporting services to explain and invite people to their screening appointments.

Whether a person has their AAA screening appears to be very much dependent on the surgery they are registered at, however reviewers have seen evidence of easy read written information given and the AAA screening process explained to the individual during the learning disability AHC.

9.4 Vaccinations

We can look closely at the uptake of pneumonia vaccines for those eligible. Chapter 25 of The Green Book of Immunisations[14] 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[15], Learning Disability is still not included in in this.

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[14] https://www.gov.uk/government/publications/pneumococcal-the-green-book-chapter-25

[15] https://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf

Of the 23 reviews, where the persons leading cause of death was a pneumonia, 18 (78%) 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 these 18 reviews, 10 had evidence of having a pneumococcal vaccine, meaning 44% didn't. Although still not ideal, this is an improvement on last year. These figures do not include the 4 cases with a pneumonia as an 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[16]. Uptake of the flu vaccine has been maintained since last year, with 86% (*n*=54) of all completed reviews having evidence that the person had a flu vaccine regularly.

Of those within the age bracket for the Shingles vaccine, only 29% (*n*=9) had evidence of having had it in their review. The COVID-19 vaccine is a safe and effective vaccine and began distribution from December 2020. Over this year the eligibility criteria for a seasonal COVID vaccine have changed, as such we will be no longer recording the number of vaccines people have had, and instead review administration in the same way for pneumococcal/flu vaccines. Over this year Respiratory Syncytial Virus (RSV) vaccines have also been introduced, which we have started to record as part of our post review work and will begin to report in next year's annual report.

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[17]. 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.

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

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

- 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 63 reviews.

Gender	**<18**	**%**	**19-24**	**%**	**25-29**	**%**	**>30**	**%**
Males (*n*=33)	<5	*3%*	14	*43%*	11	*33%*	7	*21%*
Females (*n*=30)	<5	*3%*	15	*50%*	6	*20%*	8	*27%*
Total (*n*=63)	<5	*3%*	29	*46%*	17	*27%*	15	*24%*

In the 63 completed reviews both men and women mostly had a healthy BMI recorded. We have a reduction in the number of people classed as underweight and obese but a higher percentage of people falling into the overweight range. Overall, men had a higher combined percentage of reviews falling into the overweight and obese ranges than women. Similarly, a higher percentage of all the reviews had a combined BMI in the overweight or obese range compared to the healthy range. This is the same as last year.

Learning identified by reviewers:
Many reviews show individuals with a learning disability having a high BMI. There does appear to be general advice given for healthier lifestyles such as at AHC including encouraging uptake in exercises and eating a healthier diet. However, it is clear this is not always adhered to, and we see consistent high BMIs across multiple years. In some cases, reviewers see involvement from the specialist learning disability dietitian, but despite specialist intervention, outcomes are limited where there is assessed capacity and more independent living.

Support often includes education, help with menu choices and care planning. Weight loss is managed incredibly well with effective use of The Malnutrition Universal Screening Tool (MUST) and supplements to avoid someone becoming underweight. Some lower tier weight management support is not always suitable for individuals with a learning disability. Advice for self-referral to a weight loss programme doesn’t seem to be effective for individuals with a learning disability. Secondly, where intervention is put in place there seems to be little evaluation or review of progress and to see how this impacted their life and weight, despite returning for AHC where BMI is consistently high. This is especially important where consideration is needed of (sometimes weight related) co-morbidities.

9.6 Body Mass Index (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[18]. Of our completed reviews, 59% (*n*=37) had evidence of psychotropic medications being prescribed, this is an increase of 20% 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, 51% (*n*=19) had a BMI considered overweight or obese, which is similar to last year.

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

STOMP[19] 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 autistic people, 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, 73% (*n*=27) of people who were prescribed psychotropics, had them for a mental health condition or to support in behavioural management, and 63% of those (*n*=17) had been on psychotropics for over 5 years. Both of these figures represent a lower percentage than last year.

The most common singular reason for a psychotropic being prescribed was again due to a mental health diagnosis, present in 13 (35%) reviews. 27% (*n*=11) 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.

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

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

Most people prescribed psychotropics had a moderate learning disability, followed by mild and then severe and profound which both had less than five. Our autism only reviews may represent a smaller number of the total people prescribed psychotropics, but it is important to note this is six of the eight total autism only reviews were prescribed psychotropic medications. Last year a total of 39% of reviews were prescribed psychotropic medications, this year 59% of reviews had psychotropics prescribed. Some of this increase may be explained by our increased autism only reviews.

Learning Disability	Mild	Moderate	Severe	Profound	Autism only
Psychotropics prescribed	10	17	<5	<5	6
Percentage	27%	46%	XX	XX	16%

Learning from the reviewers:
The majority of medication reviews are completed during learning disability AHCs or long-term condition reviews. Many reviews have seen clinical pharmacist oversight which triggers a task to the GP to consider the efficacy, necessity and interactions of medications. Where we have seen no or poor medication reviews there have been examples of non-concordance with medications not being picked up and managed, people using medications on repeat prescription for months or years where the initial course was meant to be weeks and a lack of response to medication related side effects.

When a specialist medication is prescribed and not reviewed by secondary care, this sometimes is also highlighted to be actioned. However, not all individuals are having a clinical pharmacist review. There is little evidence of assessments used to gather the efficacy of the medication for those individuals who lack capacity, for example antidepressant medication where there is a need for titration or changes to reach a therapeutic level.

Reviews have seen incidences of autistic people prescribed psychotropic medications, in some instances antipsychotic medications, to manage dysregulation, irritability and behaviour with no diagnosis of serious mental illness, psychosis or a formulation present. Overdosing on stockpiled prescribed and/or illicit substances has been seen, despite risk assessments and mitigations in place such as weekly prescribing. In other cases, we have seen poor monitoring and oversight of long-term high dose antipsychotic use. Inversely, we have also seen where signs of antipsychotic side effects have been noted under a shared care arrangement with primary care, but not actioned for a medication or psychiatry review.

In most cases, oversight of antiepileptic medications is done well with specialist oversight where required and good shared care arrangements. There are incidences however where people have not been monitored to NICE guidelines, evidencing missed opportunities for specialist review and monitoring.

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[20]:

- 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 anticipated that all our reviews for people with a learning disability (*n*=55) may have required a capacity assessment at some point in their care. From the reviews 78% (*n*=43) had evidence of a capacity assessment being completed, 16% (*n*=9) of reviews described adherence to the MCA as variable, and less than 5 reviews had no evidence of a capacity assessment having been completed at all. This performance is much better than last year with more people having evidence of MCA assessments being completed and less evidence of variable compliance.

Learning from Reviewers:
Reviewers find that although usually the MCA is appropriately and effectively used in acute settings, where non-urgent decisions on future care planning or elective surgical procedures are made, there are significant missed opportunities for more collaborative and MCA compliant processes. For example, noting early enough the requirement for an Independent Mental Capacity Advocate (IMCA)

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

and making that referral to support any best interest decision making. IMCA allocation still take long time, which is not ideal when a decision needs to be made for the individual, but this can be mitigated by earlier identification and requests for assessment and support. Reviewers have seen, on occasion, assumptions being made about a person's ability or concordance with interventions such as scans. This has been with little to no consideration for reasonable adjustments around communication, de-sensitisation work or indeed consideration of capacity and best interest decision making. Reviewers have seen the challenge faced by services supporting young people from children to adult services and the conflict between parental consent and the applicability of the MCA at 16/17 years old. Overall use of the MCA can be described and variable with ongoing difficulties with accurate recording of decision-making processes which fully represent the voice of the person at the centre of the decision being made.

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, and the percentages are largely the same as last year.

DoLS Used	Number	Percentage
Yes	14	22%
No/Not Stated	46	73%
Not Applicable	<5	XX%

Learning from Reviewers:
Reviewers have seen very few cases where a DOLS was in place, when one was required. This is most notable in community settings. Following the expiry period of an urgent DoLS application, a person should have an assessment before a standard DoLS application is made. Due to capacity these assessments were not often seen to have been completed, and an application for a standard DoLS appears to be made automatically or the DoLS continues until the assessment takes place. However, reviewers have also seen good practice in supporting a person to challenge their DOLS, referring to and involving support services such as the IMCA to ensure the decision process was person centred and robust.

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, 41 (65%) had evidence of the person being on an end-of-life plan before they died, which is a slight increase to last year. The length of time on an end-of-life care plan varied from a couple of days to over six months, but most were cared for under an end-of-life plan for less than one week before they died. A higher percentage of people who died on an end-of-life care plan, died in the acute setting. However, the percentage of reviews demonstrating an end-of-life care plan where they have died at home has increased. This year we had less than 5 deaths in hospice, but more than last year. 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*=41)	22	54%	17	41%	<5	XX%	0	0%
No (*n*=22)	10	45%	9	41%	0	0%	<5	XX%

Learning from the reviewers:

Acute teams could be more aware when they are discharging a person home, if they may soon require end-of-life care and make the necessary referrals for planning and support. Too often reviewers see a person who has had a gradual decline, discharged from hospital, perhaps with a hospital avoidance plan and an understanding that they may soon become end-of-life, but without any referral to or acknowledgement or planning with community teams. Where admission avoidance planning is undertaken but this is not followed up with support and joint working with community and home care providers, any signs of deterioration, especially out of hours can easily trigger an acute hospital admission.

Palliative care teams are a vital support for the person and their carers and much good practice has been seen with their involvement including supporting families and individuals to understand end-of-life and what to expect. They also provide education for paid staff and families, while also supporting with bereavement following the death of a loved one. In some cases community services have not been aware of these services and/or how to access them. Often reviewers see anticipatory medications prescribed in a timely manner, but delivered without the necessary paperwork, for example an administration chart, which has had led to delays in carers being able to provide symptom management.

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

The Recommended Summary Plan for Emergency Care and Treatment[21] (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 51 (80%) had evidence of a completed ReSPECT document at the time of their death which is an improvement on last year. There was a lower percentage than last year of those with a ReSPECT form having died in hospital (55%), suggesting we are seeing more ReSPECT forms completed in the community. As previously mentioned, ReSPECT is a discussion which should happen as part of the AHC. According to reviews, 74% of those who had a ReSPECT document completed and a learning disability diagnosis, had attended an AHC in the last 12 months of their life, a lower percentage than last year. Of the people who were on an end-of-life plan, 95% had a ReSPECT form completed. Of those not on an end-of-life plan, 55% had a ReSPECT form completed, which is higher than last year. As such ReSPECT still may be being better used in those at end-of-life, however we are seeing more use of ReSPECT as intended, as an emergency care planning document.

Learning from the reviewers:

Completed forms often note where conversations have been had with a person close to them which is good. However, it does show opportunities to develop how we record and represent the views and wishes of the actual person at the centre of the decision. Reviewers have noted a marked increase in the quality of ReSPECT forms, where more information is generally recorded which better reflects the person it is about. Reviewers have seen certain teams building ReSPECT conversations into their standard assessment, which is incredibly positive, as it normalises the conversation and provides a good reminder for professionals to broach emergency care planning. Although many individuals have ReSPECT forms completed in the community, reviewers have frequently seen them having a new one completed in hospital every single time they get admitted, rather than the forms being shared and reviewed between services. Language continues to be an area of consideration and review. When we are discussing cognitive impairment and how this impacts on decision making, reviewers continue to see "Learning Disability" listed as a reason for a ReSPECT or DNACPR decision being made, and in one case "severe retardation".

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

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 50 (79%) patients had a DNACPR order in place before they died, with 98% of these being deemed appropriate according to the evidence available. This is a continued improvement from previous years.

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 to help people manage their anxiety and worry. • Home visits or tele health appointments by specialist teams. • Use of hospital passports and emergency admission plans. • Acute Learning Disability Liaison Teams.

	• Provision of direct access to secondary care for advice on an ad hoc basis if required.
Communication	• Information provided in clear, concise, and simple language. • Easy-read letters to invite people to attend their AHC. • Easy-read care plans provided by primary care in collaboration with patients. • Terminal prognosis delivered in collaboration with a community learning disability nurse in a language that the person could understand and then a plan for end-of-life care was co-produced with the input of the patient. • Provision of communication care plans. • Adapted communication which meets individual needs. • Time allowed for processing. • Smoking cessation information given in simple language with clear support.
MCA Principles	• Highlighting in health and care passports about a persons noted difficulty with executive functioning and ensuring staff properly test agreement or responses. • Additional appointments offered with clinical staff to reiterate and discuss treatment options. • People consulted using reasonable adjustment to contribute to care and treatment decisions, including: ➢ Moving home ➢ End-of-life care ➢ Aspects of daily living ➢ Meal planning and diet ➢ What activities to attend on what day ➢ Hospital avoidance plans
Familiar Carers	• Using the expertise of family or parent carers in best interest decision making. • Using care staff to support with end-of-life care in hospital. • Building care plans and hospital passports with carers who knew the person, paying close attention to non-verbal cues. • 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.

	• Transferring investigations to a local hospital to facilitate less travelling time and enable family support at appointments. • Prioritising familiarity for spotting soft signs of deterioration.
Bespoke Care	• Ensuring the person had the same GP and practice staff or preferred staff where possible to allow continuity of care and build trust and support engagement. • Providing bespoke equipment such as iPads to provide distraction and reassurance and reduce anxieties. • Flexible approach to community care provision allowed for access to community activities. • Adequate planning and individualised care which helped engagement for appointments, for example allowing a scan to be completed in standing position due to anxiety. • Making and agreeing the next appointment at the end of the GP appointment as this assured understanding and supporting attending. • 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 and health and care passports used to adapt ward-based care and support. • Care home taking on complex end-of-life care to enable a person to die in their home.

Theme	Examples of poor use of reasonable adjustments
Adapted Access	• Lack of consideration for access preferences to support someone engaging with an intervention, for example 1:1 counselling over group work. • Multiple transitions between different professionals within the same service led to frequent disengagements from support. • Poor documentation of required reasonable adjustments to support an acute admission. • Referral for an outpatient procedure initially rejected by the hospital as this “wasn’t available for learning disability patients”, delaying investigation, diagnosis and treatment.
Communication	• Poor understanding of a person’s perceived reality and/or their abstract thinking in communicating an end-of-life prognosis.

	• In care planning, there were no reasonable made to involve the person at the centre and instead just the carers were consulted. • Despite having signs in hospital to indicate likes and dislikes for food, this was not referenced and so the person stopped eating. • Multiple missed opportunities seen for easy read letters and information. • Reassessment of reasonable adjustment needs were not conducted despite a person's global decline, including cognition.
MCA Principles	• Risks of refusing treatment were not communicated in an accessible way, so the persons understanding of the consequences from a decision to decline cannot be guaranteed. • Best interest meetings may not always need to be strictly formalised, but documentation is required to evidence the work. • Missed use of MCA principles in the referral and use of independent advocacy services. • No reasonable adjustments used to enable a person to understand or contribute to decisions about their care and support. • Over reliance on "parental consent" for adults without evidence of capacity assessments or best interest decision making.
Provision of Care	• An inflexibility in patient transport which didn't account for the person's complex care needs led to missed appointments and had an impact on wellbeing. • There were opportunities for better planning and support to allow a person to die at home, rather than being moved into residential or nursing care. • Missed care reviews meant home care support was inadequate to meet the person's needs. • Frequent discharges following episodic care interventions led to poor outcomes and little oversight of health and wellbeing. • 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.

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 evidence of more use of reasonable adjustments than not. Again, this year we did not see any reviews where there were no examples of reasonable adjustment being used and less examples of missed opportunities to use reasonable adjustments. Although highly subjective, this is still perhaps a good indicator of progress.

Learning from reviewers:
Reasonable adjustments are not always standard practice, and on many occasions, someone must advocate or ask for them, for example having familiar staff or family present during hospitalisation or a side room to avoid increased anxiety. This shows scope for better use of the reasonable adjustment digital flag and up to date health and care passports. These should be electronically added to someone's file where possible. From an acute setting and community setting what is consistently seen to lead to a good use of reasonable adjustments is the involvement of learning disability specialist teams. The value of these colleagues cannot be underestimated and is evidenced in the reviews.

There is evidence of good reasonable adjustments such as taking time to explain procedures using adapted communication methods including pictures and simple sentences to maximise understanding minimise anxiety. People are being offered appointments at a chosen time of the day, where it was better for them and therefore, they were more likely to attend. We have seen appointment reminders and a wider offer of home visits for individuals who are unable to attend the surgery. There is good reference to familiar staff or family during appointments or interventions, and in some cases, investigations are being completed in outpatients to minimise hospital stays. Furthermore, we have seen multiple investigations arranged for the same day to avoid unnecessary trips to hospital.

Some poor examples have included hospital transport not accommodating for the time it takes for a person with complex and profound physical and learning disabilities to get ready to leave home. An automated approach to hospital appointments can mean missed appointments. Some services focus on "episodes of care", has meant we have missed the opportunity to provide an extended period of case management and support which has led to a rapid deterioration post discharge. Care co-ordination is also important and where a lead professional is missing, gaps in care provision are usually apparent including specialist monitoring from secondary services and medication reviews.

10. Safeguarding

Reviewing the deaths of people known to have a learning disability and/or autistic people helps us 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[22] 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 bi-monthly and to the Learning Disability and Autism Programme Board monthly, to share key learning with representatives from the wider NHS providers and the ICB's Safeguarding Team.

Over the last year our team has had one review be referred 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 seen multiple instances of missed opportunities to refer to safeguarding, including in cases of self-neglect and/or domestic violence where concerns have been raised and noted by several professionals. Good transition arrangements for young people are incredibly important, especially where there have been adverse childhood experiences, safeguarding involvement

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[22] https://www.rcn.org.uk/Professional-Development/publications/rcn-adult-safeguarding-roles-and-competencies-for-health-care-staff-011-256

and/or mental health support. We have seen inappropriate discharge from mental health services at transition age, rather than a transition arrangement into adult services, which has led to fluctuating mood and self-harm.

11. Examples of Lived Experiences

This section is about the stories of people whose life and death, we have reviewed. They have families and friends who cherished them therefore, we are sharing some of the stories and experiences from completed reviews. The details have been anonymised and names changed to further protect their identities.

Liam

Liam was a 44-year-old man with a mild to moderate learning disability, living in supported living accommodation. He was described by those who knew him well as kind, funny, spirited and having a personality that was “larger than life”. Liam loved playing the guitar, going to bingo and had a passion for cars. Liam had a period of weight loss and was under investigation with the GP when he was admitted to hospital for an infection but was diagnosed with colon cancer with extensive liver metastasis.

Our review found that reasonable adjustments were applied consistently in supporting this person during their last hospital admission including the investigations and his diagnosis. He was supported by familiar staff who provided comfort which reduced Liam’s anxiety and increased his engagement but also provided effective communication with professionals and family. Following multidisciplinary discussions, it was agreed treatment was not a viable option and Liam was to be referred to palliative care.

On discharge there was excellent communication and liaison between a multitude of professionals from different agencies to meet Liam’s palliative care needs and provide excellent end-of-life care in the place he called home. His home worked with his family and friends to make sure Liam always had someone there so at the time of his death, he was comfortable and surrounded by loved ones.

Glenda

Glenda was a 50-year-old lady with a mild learning disability, secondary to a genetic syndrome with other health conditions. She lived with a foster family under the shared lives scheme. People who knew her described Glenda as a happy person who smiled a lot and made friends easily. She liked watching TV Soaps and listening to music on the radio. Glenda was needle phobic and not happy with any medical procedures, despite desensitisation, reasonable adjustments, encouragement and even mild sedation. Glenda didn't have any vaccines, screening or many blood tests.

Glenda had experienced a period of changing continence needs. Eventually she was referred to the community learning disability team for desensitisation work for her to accept some blood tests, while she received antibiotics. Following abnormal blood test results, clinical examination revealed a mass, and a 2-week referral was made to Gastrointestinal Medicine. While waiting Glenda was admitted to hospital with an acute kidney injury and found to have an extensive cancerous tumour invading her bladder uterus and ovaries. Glenda was deemed not fit for radical treatment and was discharged home for end-of-life care.

Her review noted there were opportunities when Glenda's continence presentation changed, to offer a referral to a urogynaecologist, as per the NICE CKS guidance. This would have been beneficial as early referral to secondary services, could have diagnosed her cancer at an earlier stage when it could have been treated, while also it may have avoided the need for blood tests, as Glenda was needle phobic.

Louise

Louise was a 79-year-old lady with a severe learning disability who had recently moved into a care home due to a change in her needs. Louise was described as feisty and loved 1:1 time with staff. She liked reading, listening to music and watching TV, especially soaps and Tipping Point. She was a real animal lover, especially cats and dogs. Louise had a complex health profile. Her review showed she was prescribed an antipsychotic medication, yet there was no review from secondary mental health services to evaluate its efficiency or necessity. More so, the GP records show that the reason the medication was prescribed was "learning difficulties".

In the 18 months before her death Louise presented with a significant health deterioration, including multiple attendances to ED and hospital admissions for a variety of reasons. Louise had a bowel care plan designed to manage her complex needs. Louise's home didn't have nursing provision so their staff attended additional training to facilitate this care and Louise could stay in familiar surroundings with familiar people, without a reliance on district nursing. This worked very well, and was supported by an excellent relationship with the GP surgery who would visit weekly for "ward rounds".

Louise was felt to be approaching end-of-life so it was agreed a hospital avoidance plan would be in her best interest. Unfortunately, Louise still required the odd admission where community management wasn't effective. When Louise entered her end-of-life stage, she had palliative care focussed on symptom control and comfort and she was supported to peacefully pass away, at home, with family by her side.

Adam

Adam was a 72-year-old gentleman with a mild learning disability who lived with family, in the same house he has grown up in as child. Adam was described as quiet, happy, kind and fiercely independent. He liked to go to the allotment and enjoyed going to local cafes, shops and spending time with his family. Adam was generally well and the care and support he received from his family was outstanding.

Adam had experienced a steady deterioration in his health but was clear he wanted to keep living at home. Following a care act assessment a Direct Payment arrangement was agreed with family members acting as a personal assistant but unfortunately, he passed away before this could be started. Family was consistently included in his care and support planning, including in the end-of-life discussion when Adam became acutely unwell and wasn’t responding to treatment.

It was decided that it was in Adam's best interest to stop treatment. Unfortunately, he was too unwell to go home but staff worked to keep him comfortable and anticipatory medication was prescribed. His care planning moved to symptom control and comfort and Adam peacefully passed away with his family by his bed side.

Lorraine

Lorraine was 72-year-old lady with a mild to moderate learning disability. She had been an inpatient in a hospital for over 30 years before she moved to supported living accommodation in the early 2000s. Lorraine was described as an energetic and friendly person who made friends wherever she went. She had a very active social life and had been supported to have holidays including cruises.

Lorraine had said how she found her happiness when she moved into supported living and the move away from institutions “gave her wings". Her experiences had been used as training for care staff, and she had even given a talk to 300 staff on one occasion, as well as being involved in staff recruitment. Lorraine’s review really highlighted the importance of suitable and appropriate accommodation on an individual's wellbeing, especially after being subject to institutionalism in the past.

Lorraine had some blood tests after a period of illness which were deranged and so her GP arranged for Lorraine to go to ED for further investigations. Staff were aware that Lorrane had a learning disability and was becoming increasingly distressed and agitated by the long wait and busy environment. However, she had to wait 7 hours to be seen then told she needed to return the next day for imaging. On her return the next morning, the same thing happened, and Lorraine had to wait until the afternoon. There was no consideration, or offer, of reasonable adjustments.

Unfortunately, Linda was diagnosed with cancer. The home worked well to explain Lorraine's condition and prognosis to her in a way she would understand. This enabled Lorraine to decide that if the treatment wasn't curative, she didn't want it just to prolong her suffering. Before a plan for her cancer management could be arranged, Lorrane became acutely unwell and was admitted to hospital but didn't respond to treatment. In conversation with loved ones, it was decided to commence palliative care.

Lorraine was too unwell to be transported home for end-of-life care but was supported in hospital by the palliative care and the acute learning disability liaison team. Family and carers took turns to always be with her and she passed away peacefully with her siblings at her bedside.

Dawn

Dawn was a 58-year-old lady with a mild learning disability. She had her own tenancy through a housing association. She was very independent and liked to get out in the community and see her friends.

In the couple of years leading up to her death, Dawn didn't attend her health appointments, including screening, vaccinations and annual health checks. Historically Dawn had been difficult to engage in services and case management was challenging with Dawn's very complex health and social care profile. When services were involved, there were notable areas of collaborative work including in decisions on maintaining her tenancy agreement to avoid eviction, management of hoarding including decluttering and house cleaning, supporting Dawn to attend appointments and raising and sharing concerns for her safety and wellbeing with safeguarding colleagues.

Most notable was the support from the Health Improvement Team who worked to encourage Dawn to attend her annual health check. The team visited Dawn at home to talk to them, explained what the health check was and talked about how it could be beneficial. Moreover, the team supported Dawn to attend the appointment at the surgery, which opened many opportunities for support and signposting including vaccination, smoking cessation, dentistry and the opticians.

Unfortunately, Dawn did tend to move through periods of disengagement with services where any improvements made would then backslide as Dawn would be discharged from services. There were concerns here especially due to the repeated and historical reports of domestic violence. Dawn would have benefitted from longer term, ongoing support and time to build a relationship with professionals, rather than episodic care. During a social care visit, Dawn was found in bed and not very well. She was taken to hospital and despite initially responding to treatment, quickly deteriorated and passed away in hospital.

Anna

Anna was 47-year-old lady who had a relatively recent diagnosis of autism and ADHD. Anna loved painting, reading and sewing. She was very crafty and made wreaths at Christmas and loved to bake. Anna has experienced a mixed anxiety and depression disorder for many years.

Anna received support to manage her mental health from her GP, who reviewed her regularly, and she had been open to local Mental Health Services. In recent years Anna had spoken to both her GP and Crisis Team about thoughts of suicide and self-harm, and so had a safety plan put in place with options and contacts available for Anna to speak to if needed. The safety plan was devised by the Crisis Team and the GP would reiterate it during appointments ensuring Anna knew who to contact if needed.

However, Anna had been on the waiting list for 2 years for a gynaecological procedure and had chronic pain which impacted her mental health and wellbeing. As such her suicidal ideation persisted. Her GP did regularly review her mental health and pain and a big protective factor for Anna was her dog, which sadly died and not long after Anna attended an appointment with her GP and informed them that she had taken an overdose. The GP, in agreement with Anna, referred on to the Crisis Team.

Despite contacts from the GP and Crisis Team, Anna was unreachable. Contact was made with the police to carry out a welfare check however they advised GP to do it as they had been last person to see her. A practice nurse visited and found Anna unconscious so gained access to the property by climbing through a window and commenced CPR. Anna was taken to hospital and required an ICU admission, but her condition was poor, and she passed away a few days later. Despite her history and evidence of combined drug toxicity, suicide was not recorded as a cause of death.

Lorna

Lorna was a 52-year-old lady with a diagnosis of a moderate learning disability and autism, who lived in a care home. Lorna was an incredibly sociable lady and enjoyed doing arts & crafts with her friends. She loved music, especially ABBA and hymns at her church. She liked baking, the seaside, shopping, and was very keen to make sure she looked nice.

Lorna had bipolar disorder and had regular contact with the learning disability psychiatry team. It was noted in the review the impact of Lorna seeing the same consultant psychiatrist, who monitored her mental health and having had an in-depth knowledge of her condition, knew what had worked in the past and what had been trialled, so could make informed decisions in terms of therapeutic input.

Where Lorna did struggle with her mental health, and presented with behaviours that carers found challenging, there was evidence of good collaborative work from multi-disciplinary services in, avoiding the need for admission, reviewing positive behaviour support and communication care plans and reviewing her medication as per STOMP protocols. A lot of this work involved Lorna's social work team, despite them being out of county.

Unfortunately, Lorna required admission to ED following a cardiac arrest after choking at home. This was later found to be due to a previously unknown food allergy. Unfortunately, the extent of Lorna's brain damage mean recovery was unlikely. Discussion took place with family and carers, and it was agreed Lorna would be referred for palliative care. She was transferred to a side room; her care was focussed on comfort and symptom control, and she peacefully passed away with her mother by her bedside.

Gerald

Gerald was a 67-year-old gentleman with a severe learning disability who lived in supporting living, with family and a home care package. Gerald was described as shy and liked long walks outside. He loved going to see his football team play and take trips out to London see the theatre and museums.

Gerald had been quite unwell for a few years before he died, however despite multiple acute illnesses he repeatedly rallied. His complex health profile and steady deterioration in health required support from many services. The GP practice had two doctors allocated to their service meaning if one GP wasn't available the other who knew the residents well would either call or visit. The community learning disability team supported with nursing assessment support and referrals. Gerald had ongoing reviews with the psychiatrists and the physiotherapist and occupational therapist supported with mobility, providing aids and equipment as Gerald became more reliant on support.

A comprehensive admission avoidance plan support plan was created including oxygen, stand by antibiotics, a review of his ReSPECT document and provision of anticipatory medication. This plan was effective and in the last few months of his life Gerald had increasing seizures, and the community specialist epilepsy nurses were very responsive to requests for support in managing them. Due to this multi-disciplinary working, with support from his care provider, GP, community learning disability team, and local community nursing team, Gerald remained in his home for his end-of-life care as he wanted.

Patrick

Patrick was a 70-year-old gentleman with a mild learning disability and a longstanding and complex history of mental illness. Patrick had spent periods of his life admitted to hospital under sections of the mental health act, and more recently before his death was admitted to a nursing home with 24-hour support. Patrick was a very private man but enjoyed time in the garden.

The GP surgery conducted a weekly "Ward Round" which included reviewing every resident at least once per month, ensuring good oversight and quick identification and response to deterioration and concern. Also keeping the GP involved meant primary care, mental health and other services worked well to coordinate Patrick's care and support. Patrick had good oversight from the community mental health team with regular reviews which included medication reviews focused on STOMP principles and crisis planning.

Patrick had seen an overall deterioration in his physical health, including his swallow, and was having repeated chest infections. A long-term plan for his eating and drinking was discussed as Patrick had not been concordant with his assessment and has been unwilling to keep in a naso-gastric tube. This was a multidisciplinary discussion including relevent specialists, mental health input to assess for an acute psychiatric cause and an IMCA. Surgically placed feeding tubes were deemed inappropriate, and the team took a best interest decision to pursue palliative management with an Eating and Drinking with Acknowledged Risk (EDAR) and admission avoidance plan. He was discharged with an end-of life care plan which enabled him to pass away at home in the comfort of his own room.

Peter

Peter was a 55-year-old gentleman with a moderate learning disability and a complex health profile requiring support from multiple services. Over the years he lived in several care homes, with his most recent moves being a result of a change to his heath and care needs. Those who knew Peter described him as 'happy go-lucky' and very sociable with a good sense of humour. He liked arts and crafts, helping in the office, spending time with animals and going to the gym when his health allowed.

Although initially Peter was independent with some of his activities of daily living, due to frequent periods of ill health and hospitalisation, Peter became more and more dependent on staff. Yet staff really worked to help Peter fulfil some of his bucket list wishes, including a day at a racetrack where he got to ride in supercars. They even had plans to take Peter to the Titanic Museum in Belfast but unfortunately, he passed away before they could go.

Peter's dysphagia led to recurrent chest infections so preventative measures were taken to minimise the frequency of aspiration incidences, but these were unsuccessful. The review highlighted how liaison between teams collaboratively with Peter and his family, resulted in timely and person focused decision making, which coordinated multiple aspects of Peter's care. This was best seen in the decision making around his eating and nutrition and respiratory care.

During his last acute illness Peter had a sudden deterioration. Despite treatment, Peter's condition didn't improve, and he was palliated with care focused on symptom control and comfort. He peacefully passed away the same day with family and carers by his bedside.

Rebecca

Rebecca was a 45-year-old woman who resided with her partner and their cat in a supported living accommodation. She had recently moved from private accommodation due to a change in her needs. Rebecca was described as a happy person. She loved going out with her friends, watching TV, especially soaps and listening to music. Although Rebecca had a mild learning disability within the context of her genetic syndrome, she wasn't on the GP's learning disability register and therefore she didn't have any annual health checks, but did have good long term condition reviews.

Rebecca had a multitude of complex and related medical conditions for which she required specialist investigations and ongoing reviews. Coordinating correspondence with multiple secondary care services was complex and time consuming for her family. However, the review also saw excellent liaison between multiple professionals in achieving the best therapeutic input for Rebecca and attempts to coordinate appointments to avoid multiple hospital trips, amongst other reasonable adjustments.

Over the last couple of years, a significant deterioration in Rebecca's condition was noted resulting in multiple and prolonged hospital admissions. Her review found Rebecca had great support from the acute learning disability liaisons team to navigate her frequent admissions which had significant benefits to her wellbeing. In this case the family also praised the chaplaincy team at hospital for their incredible support during hospital stays. Firstly, during COVID-19 when family visits were restricted, Chaplaincy visited Rebecca when her family couldn't and offered emotional support and comfort. Secondly Chaplaincy visited during Rebecca's end-of-life care, which gave them all a lot of support.

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 this is called Learning into Action. 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 and the wider LeDeR programme in 2024/2025:

- Working with community providers to better coordinate the diagnosis and management of dementia for people with a learning disability.
- Sharing information on Palliative Care Services and the support they can offer to community care services and engaging them with networking information to improve access for the people they care for.
- Sharing and promoting a drop in networking event for professionals where partners participate in a weekly multi-agency meeting where referrals are discussed, and professionals can share relevant information on a case and provide suggestions, advice, and support on different options. This good practice helps people benefit from collaborative consideration of their case management.
- Pathways have been established with community trusts to ensure everyone with a learning disability, on Clozapine, has a care programme approach (CPA) coordinator and regular reviews including use of the clozapine physical health monitoring form.
- Case summaries have been a useful way of sharing specific learning directly with services. This has been both for suggested areas of improvement while also highlighting particularly good practice that was very impactful. The team has a variety of routes to communicate learning with health and care services.
- We have shared with primary care the importance of recording emergency contacts to support welfare checks for autistic people with mental illness while also promoting Zero Suicide Alliance Training on Suicide in Autistic People.
- Exploring with autism diagnostic services how health and care passports are broached as part of post diagnostic support.
- Working with the ICB Quality Team to explore the knowledge and training for pain management services into how pain can be experienced and communicated differently in autistic people and if there is room for improvement.

- Our team has supported the creation of the ICB ReSPECT Policy as part of the working group, by feeding back LeDeR learning to influence the curriculum and where training is targeted.
- We have supported the ICB End-of-Life Programme Board with making easy read leaflets for “DNACPR”, “Advance Care Planning” and “What to Expect in your last weeks” for use in their yellow folders project, while working with Opening Doors to review and feedback.
- Our team worked with the Oliver McGowan Training Project Manager and the newly commissioned provider to incorporate local LeDeR learning into the curriculum.
- Exploring with wellbeing services their processes for safety netting and crisis and escalation planning as part of discharge, consideration of wider risk factors for autistic people in mental health triage and assessments which may indicate a risk of suicide or death by misadventure, sharing Zero Suicide Alliance Training on Suicide in Autistic People for wider distribution and staff update, improving discharge planning.
- We have shared LeDeR learning to help with service development of a new pilot programme to provide specialist intensive support to young autistic adults.
- Highlighting to mental health services the need for prescribing guidance and consideration of STOMP principles when prescribing antipsychotic medication to manage dysregulation and irritability in autistic people with no diagnosis of serious mental illness or psychosis.
- We have used LeDeR learning to inform the recommissioning of services, by ensuring new providers can meet accessibility standards.
- Following up with certain services where specific and repeated issues have been seen to explore an improvement in learning disability awareness and provision of reasonable adjustments.
- Coproduced a 7 Minute Briefing on “Talking Therapies for people with a Learning Disability”, in collaboration with Community Learning Disability Teams, including psychology and the Norfolk and Waveney Talking Therapies. In response to some learning from LeDeR this was put together to provide an update for both health and social care professionals on how and when to utilise Talking Therapies for people with a learning disability.
- Confirmed with autism services how they record and manage their waiting lists to ensure there isn’t still the opportunity for people to fall off the list, especially when waiting times are long.

- Completed a project on Emollient and Fire Risk, to include planned webinars in 2025/2026. Multiple colleagues from different specialties in the Norfolk and Waveney System have been working hard put together multiple measures to improve care in this area.
- Updating RESTORE2mini training to better provide education on identifying and communicating the soft signs of deterioration in the care sector.
- Teaching has been a big part of our continued work plan, spreading awareness and learning from LeDeR reviews, and changing practice by improving education. We have delivered training and education sessions to over 20 teams across health, social care and education over the last year.

12.2 The Health Improvement Team for Learning Disabilities

The Health Improvement Team for Learning Disabilities is an integral part of delivering the change that LeDeR promotes, to reduce health inequalities and improve the quality of care experienced by people with a learning disability. This is done by increasing the uptake and awareness of ill health prevention measures including, but not limited to, cancer screening, vaccinations and the learning disability annual health check. The teams hard work and dedication has been recognised over the year with our Health Improvement Nurse winning the NHS England East of England Learning Disability Nurse of the Year at the East of England Learning Disability Nursing Celebration. While our Health Improvement Facilitator was also nominated for NHS England East of England Learning Disability Support Worker of the Year at the same event. The team was also nominated for the Norfolk and Waveney ICB Staff Recognition Awards for ‘going above and beyond’. A full end of year report can be found in Appendix A, which details to extent of the teams work in this area. Below are some key achievements over the past year:

- Supported primary care in delivery of 76.8% of annual health checks to patients in Norfolk & Waveney on learning disability registers.
- Delivered training sessions to over 150 primary care staff in GP practices on how best to conduct a gold standard learning disability annual health check.
- Providing community outreach for 93 patients to support them to attend their annual health check, achieving this in 43 of cases.
- Attended 20 events, 29 care providers and 9 schools across Norfolk and Waveney to hold stands and/or raise awareness of the learning disability AHC, screening programmes and other health promotion and illness prevention information.
- Collaborated with the ICB cancer team in developing a charter and developing a pathway for cancer care and screening for people with learning disabilities, with data showing there has been an increase in the number of people being given advice about cancer screening.
- Adapting and launching a Pre Health-Check Questionnaire.

12.3 Looking forward to 2025/2026

Some of the workstreams mentioned above will continue into next year and develop in response to any changes. However, from the reviews undertaken in 2024/2025, we know there are areas of focus for 2025/2026:

Ref.	Focus Area Description
1.	Continue to improve the performance of the LeDeR team in completing reviews, moving us closer to the 6-month target of notification to sign off.
2.	Work to reduce the incidence of hypertension and ensure people with high blood pressure are identified early and treated effectively to reduce the impact of cardiovascular disease.
3.	Work to guide the support being offered for autistic adults, especially those with complex health and social circumstances which further impact their health and wellbeing. For example, mental health conditions, substance abuse, homelessness and contact with the criminal justice system.
4.	Work to refresh and realign good practice in the completion of MCCD to avoid postmortem diagnostic overshadowing.
5.	Improve the identification, planning and management of end-of-life care between secondary and primary care and home care provision.
6.	Continuing work to improve people’s access to an active lifestyle and support to maintain a healthy weight.
7.	Education and support for carers in identifying soft signs of deterioration and improving the knowledge and understanding of pneumonia risks (good oral care, swallow assessment, compliance with eating and drinking plans, access to vaccination) to continue the reduction of pneumonia as a leading cause of death.
8.	Improve the use of Health Action Plans as part of the Learning Disability Annual Health Check, including recording of goals, reviewing progress and sharing planning with keyworkers in the persons support group.

13. Feedback and Further Information

13.1 Previous and Accessible Annual LeDeR Reports

Our previous annual reports including our Easy Read and video version are available on our website. Our Health Improvement Team for Learning Disabilities: End of Year Report 2024-2025, referenced as Appendix A, can also be found here. The latest National LeDeR Annual Report (2023) is available online.

13.2 Knowledge NoW

People, carers, colleagues and providers can access resources for evidence-based health and wellbeing from our Knowledge NoW website.

13.3 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. You can keep updated on what NWICB is doing and/or contact us via these links:

Website Email Facebook X Instagram YouTube TikTok

14. Conclusion

The team has continued to work incredibly hard, completing more reviews again than previous years and continuing to meet its target of percentage of reviews being converted to focused. The team continues to receive a growing number of notifications, and this increasing workload means we are not completing reviews as quickly as we would like to, but the team has introduced some changes in process to help in this area. As ever our work is made possible by the contribution and challenge from health and social care providers, experts by experience and people with lived experience from across the system.

We aim to improve our data collection and collation every year, but still caution against wider generalisations or trends due to its limitations. Although subjective it is positive to see reasonable adjustments being seen so frequently in reviews, which perhaps mirrors the steady increase in scoring around Quality of Care. Yet, there remain areas for improvement in the Availability and Effectiveness of Services which will continue to be addressed where learning and action is identified.

We're pleased to again see the median age of death increase and more people living longer with a continued higher percentage of our reviews being for people over the age of 65. It is also good to see a decrease in combined pneumonias as the leading cause of death. We have more people dying in their usual residence rather than hospital, and ReSPECT forms are getting better. Yet, we still see opportunities for improved planning and management of end-of-life care.

We have seen a continued increase in the uptake in vaccinations and the work and engagement around health promotion and preventative health interventions has supported an increased uptake in screening programmes. While our area has also exceeded the national target of annual health checks for the first time, including more young people between 14 and 17 accessing their annual health checks. Quality remains an important part of this and there will remain continued work in building the value of a person's annual health check and their health action plan, as well as trying to reduce the inequality of performance across localities.
We have had the benefit of completing more autism only reviews over the last year which has led to multiple areas of action and change to improve services. There is scope for improvement here in STOMP principles, as well in the support for people with a learning disability. Yet, despite seeing an increase in prescribed psychotropics, there have been less psychotropics prescribed for "behavioural management" and less people being prescribed for over 5 years.

As we did last year, we would like to conclude this annual report by again remembering each death which has been reported. Every review represents a person with hopes, feelings and loved ones. Our leading motivation is always first and foremost, using peoples experience of care and services, to improve how we work and how we deliver care, for all people with learning disabilities and/or autistic people across our system.