

Norfolk and Waveney
Learning from lives and deaths –
People with a learning disability and
autistic people
(LeDeR)

Annual Report 2021-2022

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Foreword

Cath Byford Chief Nurse Norfolk and Waveney Clinical Commissioning Group (NWCCG) - Deputy Senior Responsible Officer (SRO) for the Learning Disability and Autism (LD&A) Programme Board

We welcome this fifth report from the Norfolk and Waveney LeDeR programme.

On 9 September 2021 the Norfolk Safeguarding Adults Board (NSAB) published their independent report 'Safeguarding Adults Review, Joanna, Jon and Ben'¹.

The Safeguarding Adults Review (SAR) outlined the lives and deaths of three young adults at Jeasal Cawston Park, of whom one, Ben, was a Norfolk resident.

The Norfolk and Waveney system fully accepted the findings of the SAR and recognised that we did not get this right and our commissioning and oversight of Ben's care was not good enough for him and his family.

The findings and recommendations of the SAR will be used as a platform for change in Norfolk and Waveney.

The LeDeR reviews for Joanna, Jon and Ben are in final stages and will be presented within the 2022-2023 report. These were put on hold to allow other reviews to conclude first.

This reporting year of 2021-2022 has seen another very challenging year for the NHS and social care and has notably shone a light on the health inequalities experienced by some of our most vulnerable population.

It has never been clearer that we have significant work to do to ensure that people with a learning disability and/or autism have equitable access to health care, and the LeDeR programme remains a key part of delivering this goal.

This report has evidenced some areas of improvement in our offer for people with learning disabilities and/or autistic people, which should be lauded. It is wonderful to see that many reviews identify good care. Our hospitals, community teams and voluntary sector must be recognised for their passion for and commitment to improving the experience of people with a learning disability/and/or autism.

We must however also acknowledge that the report identifies a number of areas for improvement. The experience of people with learning disabilities and/or autistic people who are identified within an ethnic minority will need to be a key focus in the coming months; as will considering how people with learning disabilities and/or autistic people can be supported with their physical health and, in particular, weight management, dental care² and cancer screening.

¹ https://www.norfolksafeguardingadultsboard.info/assets/SARs/SAR-Joanna-Jon-and-Ben/SAR-Rpt-Joanna-JonBen_FINAL-PUBLICATION02-June2021.pdf

² Dental care is not recorded within the LeDeR reviews however is a theme we have noted in the Safe and Wellbeing reviews for people who are inpatients. <https://www.england.nhs.uk/learning-disabilities/care/monitoring-the-quality-of-care-and-safety-for-people-with-a-learning-disability-and-or-people-who-are-autistic-in-inpatient-care/>

We have seen improvements in the number of people with a learning disability having their Annual Health Check, but we will continue to focus on increasing these numbers and ensuring our Annual Health Checks are of a high quality and standard and that individuals are appropriately placed on the GP practice learning disability register.

As we move into the Integrated Care System (ICS) in 2022/23 and focus on embedding Learning from Lives and Deaths - People with a learning disability and autistic people (LeDeR)³, the recommendations from this report will be a key factor in shaping our plan to put our learning into action.

The success of the LeDeR process is hugely dependent on the support of the family members and carers of those who have died. I would therefore like to end with my heartfelt thanks to everyone who has contributed to and helped shape this important piece of work in this most difficult of years, especially those people with lived experience; the inclusion of personal stories in this report is a testimony to them and their loved ones.

Co-Chairs of LeDeR Steering Group

Sarah Jane Ward Associate Director for Quality in Care NWCCG Co-Chair of the LeDeR Steering Group

As a steering group we have endeavoured to keep the group running amidst staff being redeployed to support the COVID-19 pandemic work. I wish to thank the members for their continued support and their expertise in reviewing the recommendations and providing strategic direction.

In line with the LeDeR Policy 2021⁴ we are revising our structure and process to include the quality assurance of the reviews through to the strategic action plan.

Much of the work of the LeDeR steering group and Learning into Action group will also link with learning from the Norfolk 'Safeguarding Adults Review, Joanna, Jon and Ben' and also from the Safe and Wellbeing Reviews⁵ that NWCCG undertook with social care at the end of March 2022.

You may note the report has changed in the content and going forward we aspire to bring you more statistical analysis and comparison as our own data base is developed.

This will be the last LeDeR report from Norfolk and Waveney Clinical Commissioning Group (NWCCG) as we become the Norfolk and Waveney Integrated Care Board from 1st July 2022.

³ Learning From Lives and Deaths - People with a learning disability and autistic people is referred to as LeDeR

⁴ <https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf>

⁵ <https://www.england.nhs.uk/learning-disabilities/care/monitoring-the-quality-of-care-and-safety-for-people-with-a-learning-disability-and-or-people-who-are-autistic-in-inpatient-care/>

I personally wish to thank everyone who has contributed to the LeDeR process within Norfolk and Waveney and thank the families and carers for providing insight into the lives and deaths of our Norfolk and Waveney residents with a learning disability and/or autistic people.

Andrew Borratt – Co-Chair of LeDeR Steering Group

Hello, my name is Andrew Borrett I am an Expert by Lived Experience as I have a learning disability and autism. I am the Co-Chair with Sarah-Jane Ward in Norfolk and Waveney; I also attend the LeDeR into Learning into Action group as well as attending the LeDeR Steering Group in my role as co-chair.

I am very proud to have held this role for 6 years. I want to see more people with learning disabilities working alongside health service professionals to do real coproduction to help improve people with learning disabilities' lives and health in Norfolk and Waveney.

It is very important that deaths are reported so health professionals can review what could have been improved or prevented and what support people had with their health conditions.

It has been another tough year with Covid let alone families who have lost loved ones. I was sad to see that 13 people with learning disabilities lost their lives to Covid this year. It is important that people are given clear information to make a choice if they want to have the jab for Covid or flu so they can give their consent.

I have sat and listened to the investigations on people's deaths and helped health professionals think about how and why things happened that way for that person. I am pleased to read that more reviews than ever have been completed and less cases have been brought forward this year. I would like to thank the reviewers for their hard work during these difficult times. I am always moved by how the investigating officers work hard to find out details of who the person was, how they lived their life and who they were.

Things I have helped change:

I am excited to be involved in delivering health check training to people with learning disabilities across Norfolk and Waveney jointly funded by CCG and Opening Doors. I have been working with other experts by experience at Opening Doors to run training for Pharmacy and Speech and Language Therapy students at UEA. We taught them about the importance of good communication, making things easy read, not over prescribing medication (STOMP) sharing our health stories for them to learn from.

I chose the award to present from Opening Doors to Rebecca Crossley and the team from James Paget hospital for their accessible Covid 19 vaccination work for people with learning disabilities.

As co-chair of the steering group I would like the team to keep up the hard work in investigating and preventing people's deaths. From me personally I would like to say a massive thank you to all health services in helping keep me, my friends and family safe during the last year.

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Acknowledgments

We would like to acknowledge the many people who have contributed and supported the implementation of the LeDeR programme in Norfolk and Waveney during a challenging year where the impact of the COVID-19 pandemic on our communities and on those services that provide for them has been immense.

LeDeR reviews are not an investigation of a death but an analysis by reviewers to bring to life the circumstances leading up to the death and provide a portrait of the lives of the people they have reviewed.

Special thanks to all our LeDeR reviewers, health and social care providers, carers and families who have been central to supporting the reviewing process and delivering the programme. A special gratitude also to families and carers who have provided a lot of useful information about the care provided to their loved ones and their contribution on best practice and also some of the areas that need improvements.

We would also like to acknowledge with much appreciation the crucial role of the health and social care staff who diligently delivered quality care to people with learning disabilities and/or autistic people during the very challenging time of the second year of the COVID-19 pandemic.

We also thank those professionals who have contributed to the LeDeR steering group and Learning into Action group and especially to our partners with lived experience for their guidance, support and challenge.

1. Executive Summary

National Health Service England and Improvement (NHSEI) is committed to improving transparency and ensuring the deaths of people with a learning disability and/or autism are reviewed in a timely manner.

The review of people with autism commenced in January 2022 and is to inform service improvements and the commitment made to bereaved families to review all deaths.

In demonstrating this, the NHS operational planning and contracting guidance in 2020-2021 has reiterated the responsibility of Clinical Commissioning Groups (CCGs) to implement actions from the LeDeR programme.

CCGs must continue to publish local LeDeR annual reports describing their progress on completing reviews and the service improvements made from this learning. Data on the progress of review completion will be published regularly on the NHSEI website.

Going forward, this work is to be included within the Integrated Care System and Norfolk and Waveney CCG (NWCCG) is progressing with this transfer of responsibilities.

This report from the Norfolk and Waveney LeDeR programme demonstrates the work covered in the reporting period from April 2021 to March 2022. The deaths reviewed cover a longer period dating back to 2018. This is due to death reporting delays but also delays in the review completion which is addressed in section 3.

It is the aim of the LeDeR team that, for next year's report, the reviews will be more reflective of the people who have died within the 2022-2023 period as we move to completion of reviews within the six month time frame set by NHS England.

2. Introduction and Purpose, local and national

Welcome to the NWCCG LeDeR report, this is the fifth annual report in Norfolk and Waveney on the reviews of the lives and deaths of people with a learning disability and/or autism (LD&A)⁶ since the inception of the LeDeR programme in England in 2017. This is the first time that it will include autistic people.

The LeDeR programme reports on deaths of people with a learning disability and/or a diagnosis of autism aged four years and over.

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 LD&A, that some data is not available and that numbers in some sub-categories are small so must be interpreted with caution.

The people are not just numbers as presented in the report; they were people with strengths and talents and hopes for their futures. Some had their lives shortened by coronavirus (COVID-19) or other causes; others lived their best lives and some, long and happy lives.

The latest national data from 2019 demonstrates the majority (85%) of people in the UK population died at age 65 years and over. The corresponding proportion of people with learning disabilities from 2018-2019 was 38%⁷. This inequity is something we wish to address within Norfolk and Waveney and the recommendations from the reviewers seek to address alongside a programme of change within Norfolk and Waveney.

2.1 National Programme

The LeDeR programme⁸ uses the following definition of a learning disability:

“Individuals with a learning disability (internationally referred to as individuals with an intellectual disability) are those who have:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence)

with:

- a significantly reduced ability to cope independently (impaired adaptive and/or social functioning)

and:

- which is apparent before adulthood is reached and has a lasting effect on development.”

⁶ We prefer not to use the term ‘LD&A’ as we feel it is depersonalising, however we have used it where necessary in the report to shorten the length.

⁷ <http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR%20programme%20annual%20report%2013.05.2021%20FINAL.pdf>

⁸ <https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf>

For people with autism to be included within the LeDeR programme they must have a diagnosis of autism recorded within their health records.⁹

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 autistic children; the results are then shared with the LeDeR programme.

The LeDeR programme was established to review the deaths of people with learning disabilities (and now includes autistic people), identify learning from those deaths and take forward the learning into service improvement initiatives.

The programme has developed a review process for the deaths of people with learning disabilities. All deaths receive an initial review; this includes deaths with any areas of concern relating to the care of the person who has died, or if it is felt further learning could be gained. Where there are areas of concern these deaths receive either a focused review or a referral for consideration of a Safeguarding Adult Review (SAR) of the death as required.

A full explanation of the review process can be found at in the LeDeR policy¹⁰

The LeDeR programme aims to positively influence practice and policy by:

- Identifying potentially avoidable contributory factors related to deaths of people with learning disabilities.
- Identifying variation and best practice in preventing premature mortality of people with learning disabilities.
- Developing action plans to make any necessary changes to health and social care service delivery for people with learning disabilities.

We will know that the LeDeR programme is effective when the Norfolk and Waveney system can identify:

- a reduction in the repetition of recurrent themes found in LeDeR reviews.
- reduced levels of concern and areas for improvement in reviews.
- reduced frequency of deaths that were potentially avoidable or amenable to good quality healthcare.
- evidence of service improvement actions as a result of learning from reviews.

We expect the LeDeR programme to deliver:

- a positive experience of the LeDeR process for bereaved families.
- decreasing numbers of avoidable deaths.
- greater use of reasonable adjustments in health and care services for people with a learning disability and autistic people.
- better outcomes for people as a result of local service improvement projects.
- increased awareness of the main causes of death for people with a learning disability and autistic people among health and social care professionals both locally and nationally.
- improved data to inform us about the lives and deaths of autistic people.

⁹ Section 2.4.1/page 8 <https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf>

¹⁰ Section 3/page 12 of <https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf>

2.2 Reporting a death

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

2.3 Local Programme

Within Norfolk and Waveney, we are committed to improving services for people with learning disabilities and/or autistic people. We will use the framework set out by the LeDeR policy by NHS England, as explained above.

We have a dedicated team of reviewers who also will be developing and delivering learning packages to share within the health and social care environment. This will include the learning from the LeDeR reviews and how we can change or improve the way we provide services to improve the lives of people with learning disabilities and/or autism.

We recognise the need to provide a more detailed report than previous years. We have had dedicated support from the NWCCG Business Intelligence team to ensure we have data to present within the report.

3. 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 reviewers.

There has been a shortage of reviewers in Norfolk and Waveney to support the reviewing process, as the reviewers were clinical staff who held the reviewer role as an addition to their main post. We welcomed the change in the policy¹¹ in March 2021 when it was mandated reviewers were to be independent of provider organisations which meant we had to ensure we have a dedicated team of reviewers.

The shortage of reviewers was further impacted by the demands on clinical staff due to the COVID-19 pandemic and we therefore utilised the services of North of England Commissioning Support Unit (NECSU) who provided us with a team of reviewers. This has supported us in achieving the completion of 85 reviews in the reporting year.

We are pleased to say NWCCG has recruited to the reviewer and senior reviewer posts for two years with funding from NHS England.

As a result of a longstanding backlog of reviews to complete we have now completed 87% of reviews. A more detailed breakdown can be found at section 6.

¹¹ <https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf>

In 2021-2022, we worked on the changes and delivery of the Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy which was published in March 2021¹².

By 30 September 2020 the Integrated Care Systems (ICSs) were requested by NHSEI to have a plan to develop the systems required by the new policy, which we have achieved, and they include:

- Establishing a local governance group or panel, responsible for signing off reviews and agreeing actions.
- Expanding the LeDeR programme to include adults with autism.
- Delivering focused reviews where required (for people from ethnic minorities, adults with autism, or on request by family).
- Creating a larger LeDeR reviewing team, including senior reviewers, reviewers and administrative staff.

We have experienced challenges with accessing data previously captured in the national LeDeR system due to the changes in the LeDeR process in June 2021.

We have noted there are still key pieces of information missing, which are not easily accessible. The reader may notice some figures are solely taken from our focused reviews resulting in a smaller sample from which to draw learning and comparable data from last year. However, thanks to our LeDeR co-ordinator and NWCCG's Business Intelligence team, we have built our own data set.

We will continue to amend our local data collection for the 2022-2023 report to ensure we can continue to improve our learning and sharing of information across Norfolk and Waveney.

3.1 Summary findings from completed reviews across Norfolk and Waveney

Annual Health Checks (AHCs): over 66% of reviews revealed AHCs were completed. A few were noted to be of poor quality needing support for primary care to increase uptake and to improve the quality of AHCs.

Care & treatment: almost all patients had received regular reviews for known health conditions.

Health screening programmes: this data is not available to collate and this question will be added for our reviewers to complete in our local data set.

Reasonable adjustments: Reviews indicated there was variable consideration for reasonable adjustments. The acute setting demonstrated the best examples of good practice and is attributable to the support from an acute Learning Disability liaison nurse. This includes care planning with a focus on personalisation and meeting individual needs.

¹² <https://www.england.nhs.uk/learning-disabilities/care/monitoring-the-quality-of-care-and-safety-for-people-with-a-learning-disability-and-or-people-who-are-autistic-in-inpatient-care/>

There have been examples of good practice from primary care including face to face and home visits during the COVID-19 pandemic period despite increasing pressures on services.

End of Life care and care coordination: Most of the end of life care provision was provided with a plan in place, however this is mostly completed in the hospital no more than a few days before death. Reviews have shown that community services should approach Recommended Summary Plan for Emergency Care and Treatment documentation (ReSPECT)¹³ and Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR) decisions earlier and in a planned and collaborative manner.

It is also felt referrals to palliative care should be completed earlier to encourage specialist support in symptom and pain management. Most deaths occur in hospital and an approach to better end of life care may support use of hospice and/or home care. There was evidence of good co-ordinated care, Multi-disciplinary Team (MDT) meetings and joint decision making.

Keeping healthy: Weight management continues to require attention to support better nutrition and reduce Body Mass Index (BMI). LeDeR reviewers need to be consistent in recording a last known BMI, to contribute towards the data set.

Areas of improvement include the review of weight as part of the annual health check and early referrals to specialist learning disability dietetic services. Those in care homes and supported living could benefit from activities which place a healthier focus on food and carer support to engage in exercise. Mental capacity decisions are an important part of supporting decision making and primary care should be triggering this in those who are very overweight and obese.

Social care provider assessments and reviews: The inclusion of social care information from the care providers has been notably absent in reviews, except for details regarding Deprivation of Liberty safeguards or safeguarding.

LeDeR is currently reliant on Local Authority time and resource in provision of notes, and, when requested, they have been the best performing at timely provision of information. Work is already underway for better social care representation in LeDeR learning, both in reviews and at the local governance group and we hope this will be represented in the 2022-2023 report.

Staff awareness training: over fifteen professionals were trained as 'train the trainer' to deliver training to carers and families in RESTORE2¹⁴. This is a tool to support them in recognising physical deterioration and appropriate escalation to the relevant teams for timely intervention.

¹³ - <https://www.resus.org.uk/respect>

¹⁴ See further at section 7.9 below

4. Governance arrangements

In line with the changes to the National process we have created new governance arrangements to support the review and sign off, of completed reviews. As well as clear reporting routes into the Learning Disability and Autism Programme Board.

Initial reviews

Initial reviews are presented at the newly formed Local Quality Assurance Panel which is chaired by the Local Area Contact (LAC) and/or Head of Personalisation, NWCCG. The panel will scrutinise the review for quality and ascertain if the recommendations address the identified learning. Initial reviews are signed off and themes and trends are presented at the LeDeR steering group.

Focussed reviews

Focussed reviews go through the same quality assurance and scrutiny process above but are then presented at the Learning into Action Group for sign off which is chaired by either the NWCCG Associate Director of Quality in Care, the NWCCG Head of Personalisation, or the LAC. This group is attended by key operational stakeholders who will review the recommendations, care grading and good practice and learning is presented to the LeDeR steering group.

LeDeR Steering Group

The LeDeR steering group is co-chaired by the NWCCG Associate Director of Quality in Care and an individual with lived experience and is a subgroup of the Learning Disability and Autism Partnership Board. It is attended by a wide range of senior stakeholders to review identified learning, the strategic actions and quality improvement work streams. Work undertaken in this group is presented at the Learning Disability and Autism Partnership board which is chaired by the Senior Responsible Officer for Learning Disability and Autism for Norfolk and Waveney.

Reporting structures

The Learning Disability and Autism Partnership Board and the NWCCG Quality and Performance Committee receive monthly reports on the performance of reviews undertaken and the action into learning.

5. Performance and Demographics Overview

Reviewing the deaths of people known to have a learning disability and/or autistic people helps identify avoidable factors that lead to early deaths and supports services to improve their quality of care.

Providing good quality care to people with learning disabilities and/or autistic people and improving their health and wellbeing is a major step forward towards tackling inequalities within health and social care provision. This is something we are

prioritising within Norfolk and Waveney in light of the Norfolk SAR for Joanna, Jon and Ben¹⁵.

Since the start of the LeDeR programme in 2017, England has recorded 13924 deaths, 1519 of which were within the East of England region and of those 306 were Norfolk and Waveney deaths.

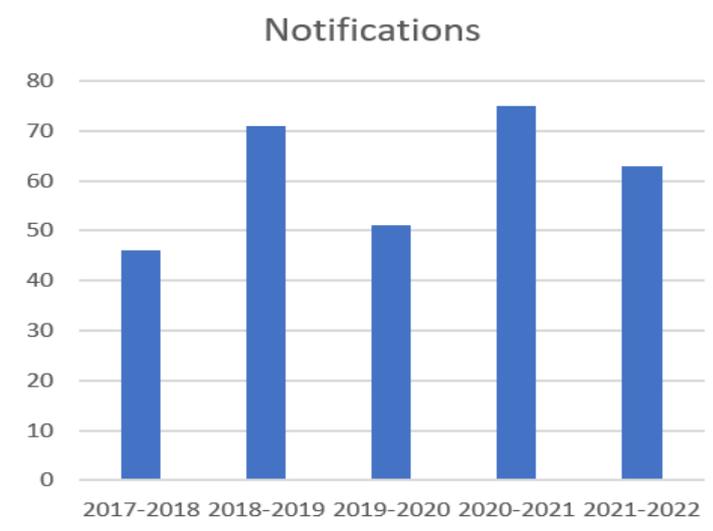
Total Number of Deaths recorded March 2017- March 2022:

England	East of England	Norfolk & Waveney
13924	1519	306

6. Notifications Overview

We carried forward 63 reviews from the previous years and, during this year, a total of 63 notifications required a LeDeR review.

The graph below shows the number of notifications over the years:



6.1 Completed reviews

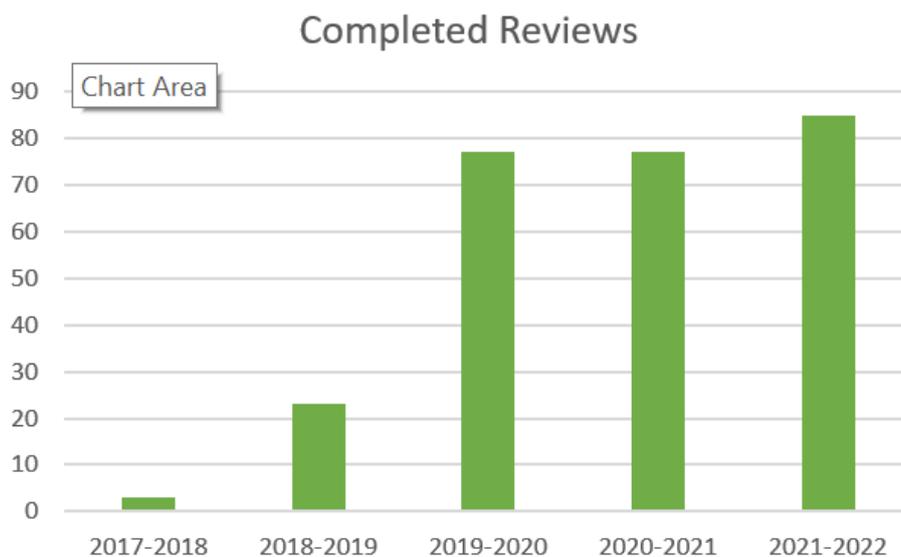
The LeDeR review performance report as at end of March 2022 shows that 87% of 306 reviews received since 2017 were completed and for 2021-22 28% (85) were completed, which is the highest completion rate since 2017.

At year end (March 2022), we have 25 reviews in progress and 16 unallocated with 9 notifications received in March 2022.

¹⁵ https://www.norfolksafeguardingadultsboard.info/assets/SARs/SAR-Joanna-Jon-and-Ben/SAR-Rpt-Joanna-JonBen_FINAL-PUBLICATION02-June2021.pdf

Years	No of 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
Total	306	265	

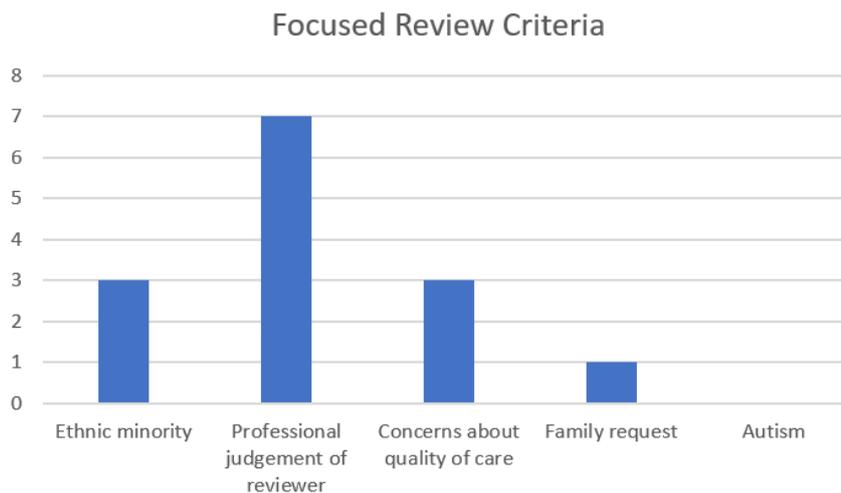
The graph below demonstrates the improvement of reviews completed:



6.2 Focused reviews (number/ percentage)

Focused reviews are required for people from ethnic minorities, adults with autism or on request by family or the reviewer. Of the 63 reviews for 2021-22, 18 were focused.

The chart and table below show the breakdown of reasons for the focused reviews.



Ethnic minority	3
Professional judgement of reviewer	7
Concerns about quality of care	3
Family request	1
Autism	0

6.3 Number of reviewers

Due to the LeDeR policy change in March 2021¹⁶ CCGs were mandated to employ dedicated reviewers with funding provided from NHS England. Therefore the posts are fixed term and we will review at the beginning of Year 2 to plan the team for the future. The table below shows the number of reviewers. The reviewers are clinicians and will be supporting education programmes to share the learning and service improvement plans across Norfolk and Waveney.

Post	Whole Time equivalents	Duration of post
Senior reviewer	1.4 Whole Time Equivalent (WTE)	2 years from January 2022 1 year from March 2022 (previous reviewer)
Reviewers	1.8 WTE	2 years from January 2022 for 2 2 years from October 2021 for 1
NECSU	Not applicable	Commissioned for 70 reviews

6.4 Performance against national targets

¹⁶ <https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf>

Reviews are expected to be completed within 6 months of notification. Due to the backlog of reviews accumulated over recent years we commissioned additional reviewers to address this backlog. This will mean future reports will have more current data and enable us to provide more timely reviews.

We were mindful that contacting families so late after their loved one's death may cause additional distress and upset and this was a priority for us to resolve.

Some reviews may take over the 6 months and that is to enable any related legal process to be completed such as police investigations, Coroner's Inquests and SARs.

The table below shows the number of reviews completed within 6 months for the reporting period.

Number of notifications for 2021-22	Number completed within 6 months 2021-22
63	18

6.5 Child Deaths

There were 3 of these deaths reported in Norfolk and Waveney. Data analysis shows that 1 (33%) was male and 2 (66%) were female. One (33%) died in hospital and 2 (66%) died at home. One (33%) died as part of a planned palliative care pathway.

Child deaths are reviewed under the child death review (CDR) process, which involves collection and analysis of information from known agencies who were involved with the care provision before the child died. This is with a view to identifying any matters of concern affecting the health, safety, or welfare of children or any wider public health concerns.

Where the Child Death Overview Panel (CDOP) has a referral for a child or young person with a learning disability aged over 4 years, they invite the senior reviewer to the panel to share in the identified learning.

CDOP has agreed to complete a referral on the LeDeR platform and share their review with the Local Area Co-ordinator (LAC) for Norfolk and Waveney which is then uploaded to the LeDeR system.

6.6 Demographic Data

This section covers the statistical data collected about the characteristics of all completed reviews since the start of the LeDeR programme. This includes age, gender, ethnicity, type of learning disability, accommodation type and place of death. In previous reports it may be noted that all reviews are graded as to the quality of the care.

During 2021-2022 the review system changed into initial and focused reviews. Under the new system only focused reviews are graded and this comprises either quality of care or accessibility and effectiveness of services.

Also covered are the main aspects of care provided to people with learning disabilities and/or autism which includes Annual Health Checks, weight management, overmedication of antipsychotic medications, provision of reasonable adjustments, cancer screening programmes, mental health and Mental Capacity Act assessments as well as end of life care.

Age ranges (percentage or number)/Average age at death/Age at death

The youngest reported death during the reporting year was 6 years of age and the oldest was 83 years. The median is 59 years of age. This year's data shows a change in the age at death from the median age of 61 years noted in the 2020-2021 Annual Report.

We are disappointed to see the median age decrease further from 62 years in 2019 to 59 years for 2022. However, during 2020-2021 and 2021-2022 we have completed the most numbers of reviews since we commenced in 2017 therefore we are likely to be seeing the true median age.

Year of death	Number of Deaths by Age Group (in years)			
	Under 18	19-45	46-64	65 and over
2017-18	0	10	17	19
2018-19	5	9	25	32
2019-20	1	11	19	20
2020-21	3	21	18	33
2021-22	3	20	27	23
Total	12	71	106	127

Gender

LeDeR data revealed that 138 (45%) of reviews were for females and 168 (55%) for males. This information is broadly in line with the national data which indicates that the age-standardised COVID-19 death rate was higher for males than for females with learning disabilities.

Ethnic Groups

Norfolk and Waveney general population data from 2011 shows 96.7% people reported themselves to be white, 0.1% to be Gypsy or Irish traveller and the population of broad minority groups to be 3.7%¹⁷.

The 2020-2021 LeDeR Annual Report did not report on any people of an ethnic minority, whilst this year 3 (4%) of completed cases were reported.

Eighty one (95%) were of white background, none of whom were of Gypsy, Roma and Travellers communities and 3 (4%) were recorded as other ethnic groups.

Level of Learning Disability severity

¹⁷ [Norfolk - Population - STP | Norfolk and Waveney | InstantAtlas Reports \(norfolkinsight.org.uk\)](#)

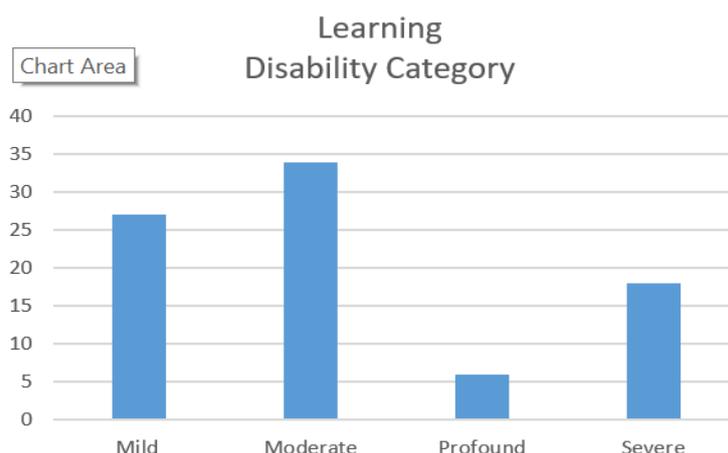
The Department of Health states ‘A learning disability, not to be confused with a learning difficulty such as dyslexia and dyspraxia, is a label given to a group of conditions that are present before the age of 18. This impacts on the way individuals develop in all core areas, and ultimately how they live their lives and access health care¹⁸.’

Approximate 1.2million of people (951,000 adults and 299,000 children) living in England are known to have a learning disability; 7,333¹⁹ of these live in Norfolk and Waveney. The total population estimate for Norfolk and Waveney is 1,032,661²⁰.

Learning disability causes remain largely unknown, however, there are known factors that could lead to a person having a learning disability such as genetics (hereditary), infections, trauma and others related to the pregnancy. Some well recognised conditions are cerebral palsy and Prader-Willi syndrome which are associated with having a learning disability.

There are four main categories of level of learning disability comprising mild, moderate, severe, and profound learning disability.

The chart below shows the distribution of deaths within these categories recorded for this reporting year.



Place of death

Most people died in a hospital setting or their usual place of residence and a few were recorded as unknown.

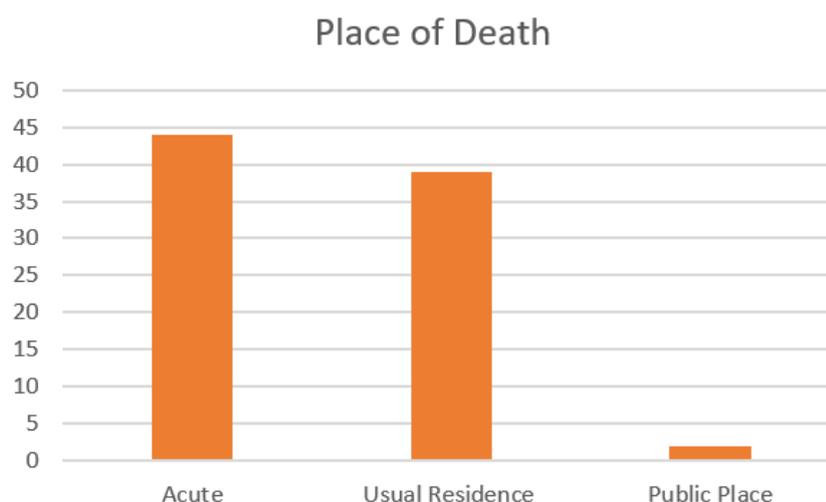
1. Hospital 44 (52%)
2. Usual place of residence 39 (46%) (own home or residential setting)
3. Public Place 2 (2%)

The chart below shows the distribution according to place of death.

¹⁸ <https://www.gov.uk/government/publications/learning-disability-applying-all-our-health/learning-disabilities-applying-all-our-health>

¹⁹ <https://fingertips.phe.org.uk/profile/learning-disabilities/data#page/1/qid/1938132702/pat/15/par/E92000001/ati/219/are/E54000022/yr/1/cid/4/tbm/1>

²⁰ [Norfolk - Population - STP | Norfolk and Waveney | InstantAtlas Reports \(norfolkinsight.org.uk\)](https://norfolkinsight.org.uk/reports/norfolk-population-stp-norfolk-and-waveney)



Although previous LeDeR Annual Reports²¹ showed that most people died in hospital settings, evidence shows that in 2021-2022, more people died in their usual place of residence or own homes compared to 2017 when the programme started.

Types of accommodation

People with learning disabilities were placed within the following five types of accommodation with the majority in supported living and residential care setting.

1. Residential care units 39 (46%)
2. Supported living accommodation 25 (29%)
3. Own homes/living with family 16 (19%)
4. Nursing care homes 4 (5%)
5. Bed and Breakfast 1 (1%)

All children were recorded as living with family. Over 75% of reviews showed that most of the adults lived in supported accommodation and residential care units.

Changes in accommodation type within the last six months of some of the people's lives were recorded, mainly from supported living or residential units to hospital care due to deterioration and an increase in patient needs.

Learning identified from the reviewers:

Reviewers recommended that before any change in care setting is made, the person should be involved in this decision and a thorough health and social care assessment completed to ensure the new placement is suitable and in the person's best interest.

6.7 Cause of Death and Quality of Care

Most people with a learning disability and/or autistic people are known to have other complex physical health complications.

²¹ <http://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR%20programme%20annual%20report%202013.05.2021%20FINAL.pdf>

Analysis of the 18 completed focused reviews show that 100% of people with learning disabilities who died had one or more physical health conditions. 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 (many people will have more than one condition recorded).

Health Condition	Number	Percentage
Epilepsy	6	33%
Dysphagia	3	17%
Cancer	4	22%
Impaired mobility	11	61%
Dementia	5	28%
Constipation	9	50%
Diabetes	2	11%
Cerebral Palsy	2	11%
Asthma	4	22%
Cardiovascular	6	33%

Causes of death (number/percentage)

NHS England states:

“People with a learning disability often have poorer physical and mental health than other people and may face barriers to accessing health and care to keep them healthy. Too many people with a learning disability are dying earlier than they should, many from things which could have been treated or prevented”²².

The most common causes of death recorded on people’s death certificates include as set out in the table below.

Health Condition	Number	Percentage
COVID-19*	13	15%
Aspiration pneumonia	12	14%
Pneumonia	10	12%
Dementia	7	8%
Cancers	6	7%
Respiratory Failure ⁷	6	7%
Heart Failure [^]	5	6%
Arterial Disease	5	6%
Frailty	4	5%
Organ Failure ⁺	4	5%
Sepsis	3	4%
Sudden Unexpected Death in Epilepsy (SUDEP)	3	4%
Bowel Obstruction	2	3%

²² <https://www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/>

*recorded also as COVID-pneumonia, COVID-sepsis, CoV SARs, coronavirus

-including acute aspiration

^including cardiac arrest

+including multiorgan and renal

Pneumonia remains the highest cause of death for the learning disabilities community in Norfolk and Waveney, with combined aspiration and other pneumonias accounting for 26% of all causes of deaths. Although the data is not available for this report, a new focus for the LeDeR reviewers is collecting information regarding pneumococcal vaccination for those who are eligible to receive this.

Cancers account for 7% of deaths and there are clear areas of learning identified for the reviews regarding reasonable adjustments and cancer screening.

Learning identified from the reviewers:

Review panels made it clear that prevention of pneumonia to be a focus for learning, evidence of vaccine administration against pneumococcal infection is low and requires recording to ascertain if there is a correlation.

For cancer care it was noted the use of capacity assessments is an important part of decision making about whether to progress with cancer screening and this was not always evident. Moreover work is needed to highlight where a person with a learning disability has not responded to an invitation for cancer screening, and a process to follow this up in person. Reasonable adjustments need to be reviewed to see if additional support can be provided to help engagement in screening programmes.

6.8 Quality of care

During 2021-2022 the review proforma changed and consequently the grading of care changed. This section will be divided into 2021 and 2022 to reflect the change.²³

2021

The review process requested the reviewer to grade the care received as based on the information they had received, or concerns raised by people who knew the person.

In Norfolk and Waveney 50% of the reviews assessed quality of care as being satisfactory or above; 50% fell short of expected good practice with 4 cases (40%) where this impacted on the person's wellbeing.

²³ Note: In comparing the three tables in this section, to note the new system reversed the numbering of the rating (first column) from ascending (table for 2021) to descending (tables for 2022).

Care of children is not graded as the Child Death Review Process has a different way of reporting their deaths.

Table showing Assessment of care received for completed reviews for 2021

Rating	Standard	Number	Percentage
1	This was excellent care (it exceeded current good practice).	1	10%
2	This was good care (it met current good practice in all areas).	nil	nil
3	This was satisfactory care (it fell short of expected good practice in some areas, but this did not significantly impact on the person's wellbeing).	4	40%
4	Care fell short of expected good practice but did not contribute to the cause of death.	1	10%
5	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	40%
6	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.	nil	nil

2022

The review process requests the reviewer to grade the care received and the effectiveness and availability of services as based on the information they have received, or concerns raised by people who knew the person.

In Norfolk and Waveney 37.5% of the reviews assessed quality of care as being satisfactory or above; 62.5% fell short of expected good practice with 3 cases (37.5%) where this impacted on the person's wellbeing.

Of the reviews, 50% assessed the effectiveness and availability of services as being satisfactory or above; 50% fell short of expected good practice with 3 cases (37.5%) where this impacted on the person's wellbeing.

Care of children is not graded as the Child Death Review Process has a different way of reporting their deaths.

Table showing Assessment of care received for completed reviews for 2022

Rating	Standard	Number	Percentage
6	This was excellent care (it exceeded current good practice).	nil	nil
5	This was good care (it met current good practice in all areas).	1	12.5%
4	This was satisfactory care (it fell short of expected good practice in some areas, but	2	25%

	this did not significantly impact on the person's wellbeing).		
3	Care fell short of expected good practice but did not contribute to the cause of death.	2	25%
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.	2	25%
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	12.5%

Table showing Assessment of availability and effectiveness of services for completed reviews for 2022

Rating	Standard	Number	Percentage
6	This was excellent care (it exceeded current good practice).	nil	nil
5	This was good care (it met current good practice in all areas).	3	37.5%
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).	1	12.5%
3	Care fell short of expected good practice but did not contribute to the cause of death.	1	12.5%
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.	2	25%
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	12.5%

6.9 Main aspects of care delivered for people with learning disabilities

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 national data and previous years. As a result of COVID-19 there was an increased number of deaths and therefore comparing with data from previous years should be treated with caution.

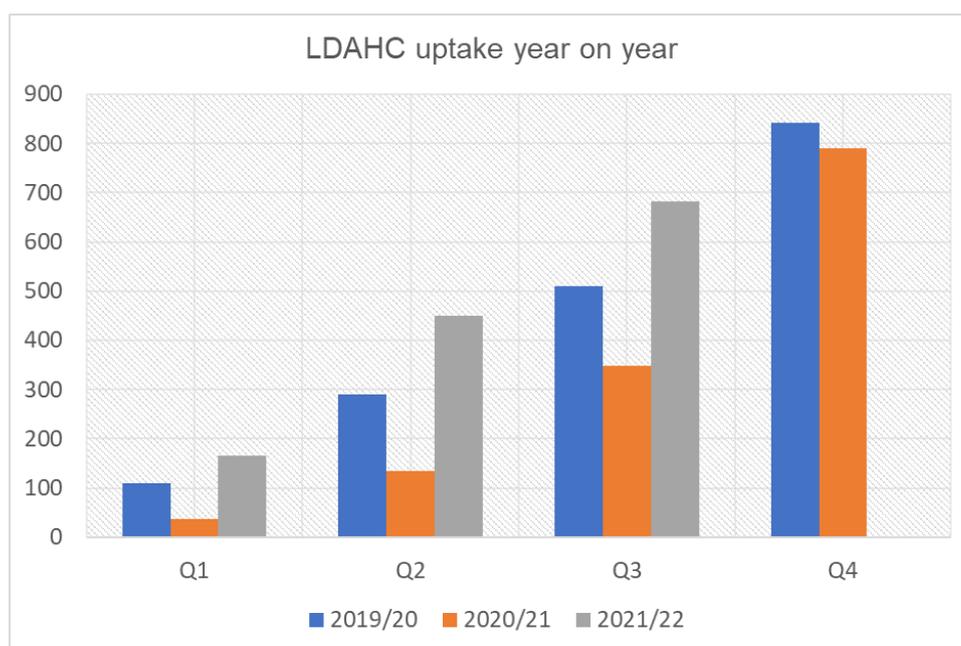
Annual Health Checks (AHCs)

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 screening²⁴.

All people with learning disabilities are entitled to an annual health check (AHC). Regular health checks help identify unmet and unrecognised health conditions, leading to early actions to address and treat these health conditions.

Fifty six (out of 85 completed reviews) were eligible for regular AHCs (aged 14 years and over). Of completed reviews, 54% had AHCs during the last year of their life. They were all individuals aged 14 years and over. For 29 (34%) reviews, reviewers found no evidence of AHCs in GP records.

The graph below shows an increase in the number of AHCs completed for all people with a learning disability across the Norfolk and Waveney system. 63.5% in 2019; this performance went down to 51.5% in 2020 due to COVID-19 restrictions. Quarter 4 data for 2021-22 was not available at time of writing this report.



AHC performance for all of the people with learning disabilities was 63.5% in 2019-2020 and 51.5% in 2020-2021 and 66% in 2021-2022; below the national target of 75% uptake of AHC for people with a learning disability.

Overall, audits based on the Public Health England Audit Tool (2017)²⁵, completed by NWCCG's Health Improvement Team, show that the GP practices have made improvements and progress in most cases. The following was looked at:

²⁴ <https://www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/>

²⁵ <https://www.gov.uk/government/publications/people-with-learning-disabilities-health-checks-audit-tool>

- AHC performance
- Identifying individuals with learning disabilities
- Arranging attendance of AHC
- Implementing Reasonable Adjustments
- Arranging follow-ups

Reviewers noted that some patients had been invited to attend an AHC but were not brought and there was no record to indicate a follow-up from the GP practice to establish why the patient could not attend and offer a further appointment.

Learning identified from the reviewers

A “was not brought” to an appointment policy is being developed for primary care to address the feedback from the reviewers that people were not attending their appointments, and most are likely to be reliant on others to bring them to their appointment.

An increased focus was on following up on patients who had declined an AHC in the previous year or not attended and an improved way of contacting patients to invite them to AHC.

The GP practices are also considering the importance of reviewing their learning disability registers and completing this regularly. However, many of practices are still not using accessible information for their correspondences with patients and not all of them are using the pre health check questionnaire before an AHC takes place.

The AHC pilot has been extended to share good practice and improve quality of the AHC for people with learning disabilities and/or autistic people.

Evidence suggests that some families and carers were not aware of the importance of supporting an individual to attend an AHC appointment. They reported not wanting to stress the individual during a settled period, or not seeing the benefit to the individual if they had experienced a below standard AHC previously.

It is clear more education to families and carers around the benefits of having an AHC being completed properly is required. This will allow those supporting the individuals with a learning disability and/or autism to question when the completion is below the recommended standards.

Reviewers recorded that patients who had received a good, comprehensive AHC were more likely to be referred for further diagnosis and treatment in a timely manner than those that had poor attendance or no checks at all.

Influenza ('Flu') vaccinations

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 (including children and people with a learning disability) that puts them at risk of flu complications.

All of the focused reviews (18 patients) were eligible for the flu vaccination, however only 44% (8) of the completed reviews indicated that they had received this during the last year of their life.

Two reviews (12%) indicated that no flu vaccination had been given. A further 8 reviews did not have their flu vaccination recorded. However prior to the move to the NHS LeDeR platform, this was not a specific question whereas vaccination status is a specific question for the new focused reviews and next year we will have a full data set.

COVID-19 vaccinations

The COVID-19 vaccine is a safe and effective vaccine and began distribution from December 2020. Those with a learning disability and associated co-morbidities were highlighted as being more at risk from severe COVID-19 complications and, as such, fell into the priority groups for being offered the vaccine.

The first vaccines in December 2020 were followed by a second dose starting towards the end of March 2021 with the booster doses starting at the beginning of October 2021.

Seven (39%) of the focused reviews had died after the release of the COVID-19 vaccine. Of the reviews, 3 (43%) had the expected number of doses for their date of death. 57% (4) of reviews showed no COVID-19 vaccination; 3 of these should have had at least one dose according to their date of death and one should have had two doses. Two of those not vaccinated showed a cause of death linked to complications from COVID-19.

7. Themes, learning points and recommendations from reviews

Learning identified from the reviewers

Reviewers noted that the uptake of the influenza and COVID vaccines were similar percentage wise. The main areas for learning continue to be reasonable adjustments to support uptake of vaccinations for those most at risk including quality annual health checks that reviews vaccinations, home visits where needed and communications methods. For example, follow up when there is no response to an invitation, consideration of easy read material, translation services or use of the community Learning Disability Teams. Capacity assessments are also an area requiring improvement, ensuring all declines to vaccines from the person or their carer trigger a robust capacity assessment and a best interest decision if appropriate.

7.1 National cancer screening programmes

Figures on the three main national cancer screening programmes were recorded. These comprise cervical screening, breast screening and bowel cancer screening.

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.

For 2021-2022, 50% of eligible people aged 25-49 years were offered a screening and 27% of eligible people aged 50-64 years were offered cervical screening.

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. For 2021-2022 43% of eligible people were offered breast screening.

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. For 2021-2022 45% of eligible people were offered bowel screening.

Learning identified from the reviewers

Reviewers felt that more needs to be done to promote the cancer health screening programme, increase uptake and for early intervention and treatment as may be indicated.

We have therefore commenced work with the cancer care/screening commissioners to seek improvements in cancer screening for our people with learning disabilities and/or autistic people.

We are also supporting primary care to facilitate accessible clinics for the screening and an education programme for carers about the importance of cancer screening appointments and home tests.

7.2 Obesity/Weight management

Evidence shows that people with learning disabilities are more likely to have poor diet and are more likely to be underweight or obese than people in the general population²⁶.

Obesity or overweight is when a person carries excess weight or body fat that might affect their health. The BMI is a measure that uses a person's height and weight to calculate whether their weight is healthy. There is increasing research evidence that BMI could be a rather poor indicator of percentage of body fat and does not capture information on the mass of fat in different body sites especially in persons with poor posture (postural kyphosis) common with persons with learning disability. Therefore, using BMI as a tool and measure, particularly for people with learning disabilities, can be sometimes be misleading.

BMI tool is currently the most used and acceptable measure of health. A BMI of below 18 means the person is underweight, between 19-24 is normal, over 25 is considered overweight while over 30 is obese. Being underweight (malnourished) or

²⁶ <https://www.gov.uk/government/publications/obesity-weight-management-and-people-with-learning-disabilities/obesity-and-weight-management-for-people-with-learning-disabilities-guidance>

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 18 reviews.

Categories	<18 BMI	19-24 BMI	25-29 BMI	>30 BMI	Unknown
Males	0	4	2	0	3
Females	0	1	1	5	2
Total	0	5	3	5	5

Analysis of the 18 completed focused reviews showed 13 (72%) had recorded BMI readings. 62% (8) were recorded as overweight or obese. 5 reviews did not record a BMI, but one did mention the person was overweight at time of death. There was a higher prevalence of being overweight in females (46%) than males (15%). Also, 38% of females were obese, where males were not represented in this category at all.

Reviewers identified that being overweight or obese was a common issue amongst people with a learning disability and this is complicated by diet, poor mobility and/or wheelchair dependency.

Learning identified by reviewers:

Information on BMI was not readily available for initial reviews as only the focused reviews currently ask for this level of detail, we will seek to amend the local data collection this will be added to the post review data collection to better inform the 2022-2023 annual report.

Reviewers found there needs to be a focus on the use of mental capacity assessments around eating where weight was an issue. There needs to be earlier and more robust management at primary care level and specialist dietician services needed to be utilised when needed. Supported living and care home environments needed better staff training and a shift in focus to support better nutrition and build more exercise into social activities.

7.3 BMI and use of antipsychotic medicines

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 drugs²⁷.

It is suggested that patients with a BMI of 25 or over should be regularly reviewed and where appropriate, supported to stop or reduce antipsychotic medicines.

Six (75%) of the 8 reviews with a high BMI (i.e. 25 or over) were known to have been on psychotropic medicines.

²⁷ https://www.bap.org.uk/pdfs/BAP_Guidelines-Metabolic.pdf

Two of the 6 reviews (33%) were known to have been on psychotropic medicines for periods greater than 5 years. However, both were for control of epilepsy.

7.4 Stopping overmedication of people with a learning disability (STOMP)

STOMP²⁸ 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, mainly comprising psychotropic medicines.

Analysis of the 18 completed focused reviews showed that 12 patients had one or more of the following conditions: epilepsy, psychotic episodes, depression, bipolar affective disorder/personality disorder, challenging behaviour, anxiety, agitation/irritability behaviour and hallucinations.

61% (11 reviews) had had psychotropic medicines prescribed. Of these, 3 (27%) were recorded as prescribed for their challenging behaviours, 4 (37%) for epilepsy, 2 (18%) for a diagnosed mental health condition and 1 (9%) as part of their end of life care. In 1 (9%) case, reviewers found no formal diagnosis or reason for these prescriptions.

64% of those with mild and moderate learning disability were prescribed psychotropic medicines compared to 36% of those with severe and profound learning disabilities. The table below shows the findings from completed reviews:

Learning Disability	Ungraded	Mild	Moderate	Severe	Profound	Total
Psychotropics prescribed	0	5	2	4	0	11
Percentage		46%	18%	36%		
Psychotropics not prescribed	1	3	1	2	0	7
Percentage	14%	44%	14%	28%		

Learning from the reviewers:

This information was not readily available for initial reviews as only the focused reviews currently ask for this level of detail.

We will seek to amend the local data collection - this will be added to the post review data collection to better inform the 2022-2023 annual report.

7.5 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.

²⁸ <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>

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.

Fifty two reviews were within this age group and eligible for MCA assessment as may be deemed necessary. 75%** of all eligible patients (39) aged 16 years and above, had mental capacity assessments or Deprivation of Liberty safeguards (DoLS) approved. No evidence of mental capacity assessments were found in 13 (25%) of the reviews completed.

The MCA states²⁹:

- 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

Learning from Reviewers:

**Many reviews noted the variable compliance with managing people within legal frameworks, as, despite capacity assessments being undertaken for some decisions, this was not consistent across all services, or indeed across one acute admission.

Reviewers also noted that the quality and accuracy of documentation was variable, and improvement was needed to demonstrate robust assessment and best interest decision making.

Deprivation of Liberty Safeguards (DoLS)

Deprivation of Liberty Safeguards (DoLS) ensures people who cannot consent to their care arrangements 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.

DoLS are 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

²⁹ Section 1 of <https://www.legislation.gov.uk/ukpga/2005/9/contents>

the same as in a care home or hospital, and the same criteria apply. However, the process is slightly different.

Analysis of the 18 completed focused reviews showed only 2 (11%) had DoLS approval. Five 5 (28%) did not have any DoLS approval in place and for 3 (17%), DoLS was not applicable. Eight (44%) reviews showed that a consideration of DoLS was appropriate, but this was not highlighted by the reviewer. This suggests training is needed for reviewers on the requirement for DoLS and accurate recording of this will need to form a part of the quality check at the local panels.

Learning from the reviewers:

DoLS information was not readily available for initial reviews as only the focused reviews currently ask for this level of detail, we will seek to amend the local data collection - this will be added to the post review data collection to better inform the 2022-2023 annual report.

7.6 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.

Analysis of 18 completed focused reviews showed 10 (55%) people had end of life plans in place at the time of their death. The end-of-life period varied between 1 day and 3 years before the person's death, but the median was 2 days. Most of these care plans were decided and put in place at the hospital during the person's last admission.

Of these 10, 9 (90%) with an end of life plan died in a hospital setting, and 1 (10%) died in their usual place of residence. 67% (6) of those who died without an end of life plan, died in hospital. Two (22%) died in their usual place of residence and 1 (11%) died in a public place. There is no data available to indicate whether people's wishes were observed in all settings.

Learning from the reviewers:

Information about the use of end of life plans was not readily available for initial reviews as only the focused reviews currently ask for this level of detail. We will seek to amend the local data collection - this will be added to the post review data collection to better inform the 2022-2023 annual report.

The reviewers reported that an earlier referral to palliative care and implementation of a care plan would aid in symptom control for the deteriorating patient. Especially pain management, which poses extra challenges for care staff due to the lack of parent and/or carer advocacy, variability of communication and interpretation of pain indicators.

7.7 Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)/Do not attempt cardiopulmonary resuscitation (DNACPR)

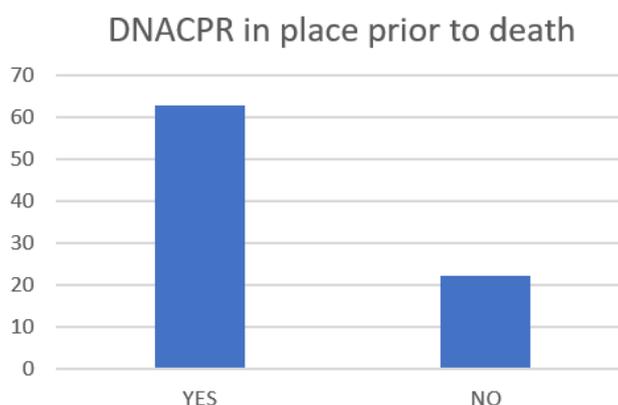
The Recommended Summary Plan for Emergency Care and Treatment³⁰ (ReSPECT) process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices.

Of the 85 completed reviews 57 (67%) were known to have ReSPECT paperwork in place, and 26 (31%) were not. In 2 (2%) of the reviews this was not known.

The guidelines state that it is good practice for decisions about do not attempt cardiopulmonary resuscitation (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.

Of the 85 completed reviews, 63 (74%) patients had a DNACPR order in place before they died. Most of these were completed in the hospital during the last few days of their life, or shortly before they died. Twenty two (26%) of these patients did not have a DNACPR order in place; most of these deaths were unexpected from sudden deterioration.

The table below shows the number of DNACPR either in place or not in place for the 85 reviews:



7.8 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.

³⁰ <https://www.resus.org.uk/respect/respect-healthcare-professionals>

A lack of reasonable adjustments can be a barrier to accessing healthcare settings.

Despite challenges due to the COVID-19 pandemic, care services adapted quickly, making reasonable adjustments to ensure equity of access to services and continuity of care. A mix of video and telephone and face to face consultations continued during the pandemic.

Looking at the reviews examined, reasonable adjustments fell into four themes, which were either accommodated or not, and are summarised in the table below.

Theme	Example of adjustments seen and/or required
Communication	<ul style="list-style-type: none"> • Use of visual cue cards. • Easy read communication to support with decision making. • Time allowed for processing. • Translation services.
Familiar Carers	<ul style="list-style-type: none"> • Parent/Carers allowed to stay on the ward. • Using care staff to support with end of life Care. • Involving familiar carers in best interest decision making. • Allowing home care packages into the acute care environment.
Adapted Access	<ul style="list-style-type: none"> • Face to face appointments. • Home visits. • Environmental controls such as side rooms. • Use of hospital passports
Bespoke Care	<ul style="list-style-type: none"> • Individualised care packages • Provision of specialist acute learning disabilities teams • Bespoke/specialist equipment • Preparatory work to reduce stress and encourage engagement such as desensitisation for cannulation.

Use of reasonable adjustments is variable across the different reviews examined for this section. For example, adjustments in communication are present in some cases and notably absent in others.

There is also evidence of variability within the same reviews. For example, some reviews have shown both evidence of adjustments to make services more accessible and a lack of adjustments which have created barriers for people to access the care they need. It is notable that the most marked difference is in bespoke care, which had the highest number of adjustments not met and the lowest number of examples of good practice.

The table below shows the numbers of reviews where the reviewers saw evidence of reasonable adjustment and the number that were required were required:

	Communication	Familiar Carer	Adapted Access	Bespoke Care
Reasonable Adjustments seen	6	5	6	1
Reasonable Adjustments were required	5	2	5	7

Some exceptional examples of provision of reasonable adjustments from completed reviews:

- a) Use of familiar carers, in absence of any family/ next of kin, to support with best interest decision making.
- b) Provision of easy read information and communication tools to support decision making.
- c) Encouraging participation of community care packages in acute settings to ensure familiar faces and consistency of care.
- d) Acute teams liaising with care staff in creating care plans and establishing base lines.
- e) Making an adapted environment part of a care plan, for example keeping a side room door open to reduce feelings of isolation and anxiety.

Whilst this report recognises that a lot has been done, more can be done in the following areas:

- a) Early assessment and provision of specialist and bespoke equipment
- b) Multidisciplinary working to locate a home/care environment which can meet needs and plan a smooth supported transition.
- c) Provision of translation services for families for who English is not their first language
- d) Using learning disabilities adapted pain scores.
- e) A more open and proactive approach to face to face and home visits where technology and accessing the community may be a barrier

Learning from reviewers:

The report also acknowledges that reasonable adjustments are somewhat hard to measure as each person's needs are different however with the new LeDeR platform, there is work in progress to put in place key information to help capture and monitor future progress on this element. NWCCG's AHC team has been working with GPs to provide personalised reasonable adjustments with the view to improving access to services therefore improved health and social care outcomes for people with learning disabilities.

7.9 Staff training

Delayed recognition of deterioration is an area impacting on the quality of care provided and in late 2021 and early 2022 NWCCG undertook the roll out of staff training on recognising deterioration and understanding the needs of people with learning disabilities.

Restore2™ is a tool designed to support care staff and health care professionals to:

- recognise when a person may be deteriorating or is at risk of physical deterioration
- act appropriately according to the person's care plan to protect and manage them
- complete a set of physical observations to inform escalation and conversations with health professionals
- contact the most appropriate health professionals in a timely way to obtain the right support
- provide a concise escalation history to health professionals to support their professional decision making

'Train the trainer' in Restore2™ tool has been delivered to 15 people in the community learning disability teams across Norfolk and Waveney. The community learning disability team's target is for all care staff to be trained by 2023.

This training has been found to be useful in supporting care staff to perform basic physical health checks which may have been otherwise difficult to undertake prior to the training hence improve the quality of care provided for people with learning disabilities. We are unable to provide data of how many people have been trained by the trainers for this report.

A QR code has been shared with providers so they can access resources to evidence based health and wellbeing from our NHS website [Care Providers \(knowledgeanglia.nhs.uk\)](https://www.knowledgeanglia.nhs.uk)



NWCCG has a team of nurses who facilitate training and champion networks for all care providers and their training programme for 2021-22 can be found at Appendix 1. All training sessions are recorded so they can be accessed at any time.

7.10 COVID-19 Pandemic

This section of the report focuses on deaths of people with a learning disability from COVID-19 and the subsequent number of full LeDeR reviews completed.

On 17 April 2020 Norfolk and Waveney reported the first COVID-19 death for a person with learning disability, in 2021-22 we reported 13 deaths caused by COVID-19 or suspected to have contributed to the cause of death.

In 2020-2021 we reported 20 deaths compared to 13 this reporting year.

COVID-19 Demographics

Age and gender

The youngest COVID-19 death recorded was aged 19 years and the oldest 97³¹ years.

Data analysis showed that 6 (46%) were male and 7 (54%) were female.

The mortality rate has decreased overall by 35% with 20 reported COVID-19 deaths in 2020-2021.

Eight deaths (61%) were recorded amongst people aged over 65 years and 2 deaths (15%) were recorded amongst children and young people aged under 20 years.

The table below shows the age and gender of those reported as a death due to COVID-19:

Age	19-45	46-64	65+
Males	0	1	5
Females	2	2	3
Total	2	3	8

Place of death

54% (7 deaths) occurred in the hospital setting, while 46% (6 deaths) occurred at the person's usual residence.

COVID-19 deaths and Ethnic Minority Groups

93% (12 deaths) were of white ethnicity and one (7%) death was of a nationality outside of the United Kingdom.

³¹ 2020-2021

8. Lived experiences of some of the people who died

This section is about the stories of people who have died. They have families and friends who cherished their lives and whose deaths will never be forgotten by their loved ones. Therefore, we are sharing some of the stories and experiences from completed reviews.

This information has been provided by family members or carers who knew the person well. Their details have been anonymised and names changed to further protect their identities.

8.1 Good Practice

Jack was a gentleman aged 83 years who had been living in his supported housing for nearly 20 years. Jack was a well-loved member of his household who loved movies, especially westerns and musicals. On his last admission to hospital there was good examples of excellent collaborative practice between the acute team and the care home staff.

The Learning Disabilities acute liaison nurses and speech and language therapy team used their expertise and knowledge of Jack to help inform and consolidate his care plans. In the absence of a next of kin or family care staff were involved in the best interest decisions regarding his move to palliative care, to ensure he was advocated for by those who knew him well. Jack passed away with familiar people around him and watching one of his favourite musicals with him.

Joanne was lady aged 71 years who lived in a supported living environment with two friends and 24/7 care. During her review her sister described her initial worries when she was moved out of a hospital environment in 2005 to community care. However, she described this as the best thing that could have happened to Joanne. She described the carers as amazing and very caring. They would take Joanne shopping and to have lunch, she went on holiday and to the theatre to see musicals. Joanne was supported to complete the Race for Life one year of which she was very proud.

Care staff supported Joanne to visit her sister and they would have lunch every week, which they both loved. Her sister described her behaviours improving greatly during her time there and her sister put this down to her being occupied and happy. Joanne's sister was clear that she felt her sister received excellent care in the last 15 years of her life and during her last hospital admission. This was a great comfort to her after Joanne passed away as she feels Joanne was happy right up until the end.

Kerry was lady aged 80 years who was kind, helpful and very sociable. Less than a year before she passed away, Kerry was moved from the placement she had been in for 7 years. There were concerns about the placement's inability to adapt to meet Kerry's increasing needs and as such family and professionals were seeing a decline in Kerry's wellbeing. Social care and the community learning disabilities team worked collaboratively to identify a new home which would meet Kerry's needs and interest. The planning process was person-centred and Kerry's transition was very planned and structured, as the new home had liaised with

Kerry's team to put in place their recommendations and care plans. This all meant Kerry settled into her new home fantastically. Family described getting the 'old' Kerry back for the last few months of her life which was very important to them.

Edward was a man aged 76 years who lived in a care home. He loved football and had a great sense of humour. Edward's experience of care at the end of his life was far from positive and the review found failing across community and acute care including poor co-ordination and communication, lack of reasonable adjustments and little collaborative working between specialties.

Edward died in hospital and a Structured Judgement Review (SJR) was undertaken. The positive practice here is the transparency and commitment of the hospital in undertaking a very honest and reflective look at their practice. The review and panel process were described as impressively frank and constructive and the LeDeR reviewer was invited to contribute to the process.

The findings from the review highlighted areas for improved practice, both from the hospital but also suggested that some of the shortcomings identified were a consequence of poor support from other systems and how this could be rectified. Usually, SJR is a single agency review but, having involved the LeDeR reviewer, it took a wider view of Edward's experience and how wider changes were needed to prevent reoccurrence.

Christopher was a man aged 47 years who was very sociable and enjoyed being outside. He liked anything to do with farms, farm animals and tractors. Christopher's last admission to hospital showed staff were very proactive in personalised care planning and making reasonable adjustments to improve his experience. Christopher was given information by staff in a way that he could understand so he was able to contribute, alongside his family, to decisions about his own healthcare.

Thought and consideration were given as to how Christopher's needs could best be met on the ward. These included being moved to a bed nearer the television to enable Christopher to watch it, with staff identifying activities to keep him occupied and reduce his anxieties around mealtimes when he struggled watching others eat. Staff also ensured Christopher was located on the main ward and not in a side room as it was felt that loss of the interaction, he had with staff in the main ward would have a negative effect on his mental health.

Family felt that the care and support that Christopher had received at the hospital was exceptional, staff went out of their way to spend time with him and ensure that he had things to do to stop him becoming bored. They stated that they had received exceptional treatment and support in Accident and Emergency (A&E), with one member of staff being particularly good at interacting with Christopher.

8.2 Areas of practice to improve:

James was a man aged 58 years who was the life and soul of his care home and had a great sense of humour. He had a pre-planned palliative care document in place from when he was diagnosed with dementia.

During his last admission to hospital the staff were proactive in speaking to the family regarding end of life planning. James' family lived far away and as such they were not able to attend the hospital on his last day when they were approached by the hospital. However, the hospital did not explore any other options to provide James with someone familiar to provide support and comfort. The care home did not feel they were able to send someone to be with James and they were not asked. James was from a religious background, but chaplaincy was not thought of, despite his religion being part of his end of life plan. Neither option was explored which led to James being alone when he died.

Gabriele was a young lady aged 19 years who lived with her family. She loved seeing her friends at school and really liked reading, cooking and Lego.

Gabriele was not brought to her appointment for her first COVID-19 vaccination. She was seen a few months later for her annual health check and there were family concerns regarding vaccine side effects. After receiving some information the family agreed to discuss this further. It would have been prudent at this stage for a capacity assessment to have been undertaken and best interest decision making discussed. Gabriele did not receive a dose of the COVID-19 vaccine and 4 months later passed away due to complications from COVID-19. Although reminders were sent, there was little consideration of the potential language and cultural barriers for this family and how more robust follow up process with interpretation services could have been helpful in educating the family.

Pamela was a lady aged 72 years who lived in a residential home. She loved costume jewellery, pampering and had a doll who was her constant companion. Pamela did not have any living family but had a great relationship with the carers at home who supported her to access her appointments. Prior to her death, Pamela had a difficult 18 months, with a delayed diagnosis and management of endometrial cancer. Communication and collaboration between specialist services, Independent Mental Capacity Advocate (IMCA), the GP and learning disabilities team were uncoordinated and led to delays, and Pamela had major health interventions without the support of appropriate services such as an IMCA or advocacy.

At the beginning of the month of Pamela's death, discussion was had to move forward with palliative care and the IMCA was consulted. Nearly three weeks later this had not been resolved and there was still confusion between primary and secondary care about Pamela's care plan when she was admitted to A&E where she died.

RESPECT forms were completed on Pamela's admission and although there was a hospital passport there was no learning disabilities nurse support on the weekend and reasonable adjustments are not seen to help identify and manage

Pamela's pain. There was also no advanced care plan or end of life plan in place which might have negated the need for a hospital admission.

Jessica was lady aged 69 years who lived in supported living and attended a day service. She loved to go out with her carers to bowling and adventure parks and was described as a bit of an adrenaline junkie as she liked rollercoasters so much.

Jessica had little face to face contact with primary care in the 18 months before she died, despite support workers concerns regarding her deteriorating health and repeated infections. Despite being registered as having a learning disability Jessica never had a learning disability annual health check.

Jessica did have reviews for her diabetes, and this became very problematic in the last year of her life requiring 3 changes to her insulin dose. It was at her diabetic review that the nurse noted Jessica had had six urinary tract infections in the previous 12 months which had not been picked up. This prompted a referral to the specialist team.

Jessica was diagnosed with cancer following a scan and passed away two weeks after her diagnosis. COVID-19 was noted to be a mitigating factor in this review due to unavoidable delay, pressures and restrictions. However, a lower threshold for face-to-face reviews with primary care may have prevented diagnostic overshadowing and allowed professional curiosity as to her overall decline.

9. Learning into Action: What happens with reviews once they are completed?

Once a review has been completed and learning identified we work with system partners including people with lived experience to make changes to services locally to help prevent people dying from something that could have been treated and/or prevented.

In previous reports you will have seen the work we have undertaken to educate people around prevention of constipation, swallowing difficulties (to help prevent aspiration pneumonia and/or choking) and why this is important for the health of people with learning disabilities. NHS England call this process Action From Learning³² but locally we call it Learning into Action.

Each LeDeR review gives us information about the cause of death of a person with a learning disability and now autistic people.

From all of the information we learn we look at what we can do locally to impact on the health of people with a learning disability and/or autism and to reduce health inequalities.

³² <https://www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/action-from-learning/>
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From the reviews undertaken so far, we know that we need to do more work in the following areas:

- respiratory conditions
- epilepsy
- cancer screening
- Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)
- deaths of people from ethnic minority communities
- weight management
- improving physical health by prevention and monitoring of treatment (including annual health check uptake)

The table below 'Learning into action from completed reviews' shows the good practice noted and the areas of improvement that we in health and social care are seeking to address and improve.

Learning into action from completed reviews

This section looks at the summary finding and recommendations and how learning from LeDeR reviews is being used to drive quality improvement activity across Norfolk and Waveney and how learning from LeDeR reviews is being used through the multi-agency Learning into Action group

Areas of excellent and good practice from reviews	Best practice identified from completed reviews	Expected Impact/outcome
E.g., good quality AHC and practice identified	<ul style="list-style-type: none"> • 54% of LeDeR reviews demonstrated completed AHC • Health Improvement Team AHC pilot has been successful in implementing improvements to GP practices' approach to AHC. • Individuals contacted by CCG Health Improvement Team to support attendance • Work commenced with 14 years to 18 years and families to highlight importance and reason for their AHC • Microsoft Teams channel has been set up to provide GP practices with education and best practice around AHC including supporting the nomination of named LD Champions within each practice. 	Reduced health inequalities, preventative care
Care and Treatment	<ul style="list-style-type: none"> • Evidence of regular reviews for all known health conditions. • In some reviews, patients were supported to stop use of psychotropic medicines. 	Timely care and treatment
Reasonable adjustments	<ul style="list-style-type: none"> • Introduction and implementation of accessible clinics • Most patients were provided with appropriate mobility equipment suited to their needs • In some cases, good communication was evidenced tailored to patients' needs, such as easy read appointment or clinic letters, text messages or telephone messages. • During the COVID-19 period, most patients had GP appointments carried out either by home visits or telephone consultation, depending on the need. LD community teams continued their support via virtual or home visits. • Most GP services provided flexible appointments and access to out of hours GP service especially for those with complex needs and those at risk of sudden deterioration. • Some Easy read information is starting to be used more regularly throughout community and acute services. 	Happier healthier lives Easy access to services

	<ul style="list-style-type: none"> • Most GP practices are recording reasonable adjustments via an alert on the home screen on their recoding system. • Some GPs practices and the acute hospitals were noted to have set up electronic alerts to flag up patients with learning disabilities when due for reviews or admitted into hospital. • Accessible vaccination clinics were set up around NW to support individuals to have their COVID vaccinations. 	
Care Co-ordination	<ul style="list-style-type: none"> • Most GPs were very involved with their patient's care coordination - liaising with other professionals and ensuring referrals were completed and teams made aware of any changes in a patient's situation regularly. • Some excellent examples of practice was identified on the use of multidisciplinary team (MDT) meetings in decision making and good communication between hospital, care homes and community teams. • In some cases, there was evidence of improved hospital discharge planning and good coordination of care. • Patients on continuing health care package were noted to have had good care coordination with a named lead. 	Care coordination is critical in ensuring smooth transition of care and continuity in delivery of quality care
Communication	<ul style="list-style-type: none"> • GPs reported using more electronic alerts containing a preferred method of communication with patients • Easy to read information was evident particularly within acute hospitals and some community services. • Some acute teams showed good communication and relationships with families during the pandemic; including giving regular feedback to family members without being asked. Excellent collaborative practice between the acute team and the care home staff. The LD acute liaison nurses and speech and language therapy team used their expertise and knowledge to help inform and consolidate care plans. 	Improved patient experience and making informed decisions.
Keeping healthy weight	<ul style="list-style-type: none"> • In one patient a good example was shown where the acute hospital worked well with the GP and care home to reduce Epilim to reduce weight. This resulted in a planned reduction in medication and referral to dietician to look at diet and exercise. This also included discussions with main carer around a healthy balance diet. • A good example was seen where the SALT worked closely with the care provider to offer pureed food in a way that would be more appealing to the individual as they had 	

	stopped eating. This had a positive outcome to the individual who gained weight within a healthy range.	
End of Life	<ul style="list-style-type: none"> In most of the end-of-life care patients, there was evidence of good co-ordinated care which ensured a seamless and dignified pathway with minimal disruption to the individuals involved. There was evidence of MDT meetings and joint decision-making taking place in a timely way. Some families and carers were provided with information they needed to make informed decisions. They were fully involved when the MCA assessments were completed, and decisions made were then made in the patient's best interest. Evidence showed that for some patients, who were referred on time, end of life care was provided in a dignified and person-centred approach. 	Seamless transition of care, avoiding unnecessary disruptions; supporting the person's wishes and preferences.
Good social care assessments and reviews	<ul style="list-style-type: none"> Appropriate changes in accommodation setting to meet patients changing health needs was recorded. In some cases, excellent mental capacity assessments and application of the Mental Capacity Act was evident. 	Personalised care package that met patient's needs.
Staff awareness training about the needs of people with LD.	<ul style="list-style-type: none"> Train the trainer in Restore2™ tool has been delivered to the community LD Teams across N&W to support care staff in recognising deterioration and taking appropriate action. The community LD teams target is to have all care staff trained by 2023. 	Prompt response to deterioration and treatment.

Areas for improvement	Proposed service improvement	Expected Impact/outcome
Poor quality AHC	<ul style="list-style-type: none"> NWCCG Health Improvement Team are working with GP practices to support improvements in AHC: Health Action Plans to be in place (and recorded as part of review) attended learning events by practice and PCN promoted use of tools supported with reasonable adjustments support to cleanse LD registers Microsoft Teams channel has now been set up to support, educate and share best practice with identified LD champions in each GP practice 	Better health outcomes for individuals with LD&A. Earlier intervention and treatment of new conditions

<p>Care and treatment of people with overshadowing diagnosis etc.</p>	<ul style="list-style-type: none"> • More appropriate referrals to the SALT team and regular reviews to ensure patients at risk are closely monitored and risk assessments are up to date. • More Efforts around desensitisation; use of exposure therapy has been recommended which can help patients gradually tolerate needles. Accessible clinics were set up to work closely with families and care providers to offer support as required. Excellent practice has been utilised to support the roll out of the COVID-19 vaccine for people with learning disabilities and Autism which could be replicated to support access to phlebotomy and other vaccinations. • GPs and healthcare professionals to be supported to reduce diagnostic overshadowing and ensure that all symptoms are thoroughly investigated. • Dysphagia working group continues to provide education and support to providers. 	<p>More risk assessments completed and reduced cases of avoidable aspiration pneumonia and choking. Early intervention and treatment of new conditions</p>
<p>Lack of reasonable adjustments</p>	<ul style="list-style-type: none"> • Comprehensive health and social care assessment to be completed and ensure appropriate reasonable adjustments are put in place to support patient needs. • Improved communication practices to meet patients' needs, including booking appointments via telephone rather than sending a letter. • Appropriate appointments (double appointments, flexible) to be provided to all patients with learning disabilities • More primary care home visits to housebound and poor mobility patients to minimise DNA's and to ensure continuity and quality of care provided. 	<p>Evidence of reduced barriers to accessing services and equity in health and social care outcomes.</p>
<p>STOMP: overmedication with antipsychotic medicines</p>	<ul style="list-style-type: none"> • STOMP working group to be developed to support education around medication reduction where appropriate. 	<p>-more STOMP awareness across professionals -more patients supported to stop overmedication of psychotropic medicines, where appropriate.</p>
<p>Poor DNAR CPR/ReSPECT documentation</p>	<ul style="list-style-type: none"> • DNACPR forms to be completed correctly and implemented appropriately. • DNACPR process to be discussed with all those involved with the person's care and only to be applied as needed. • Clinical teams to follow DNACPR NICE guidelines. • DNACPR training to continue to be provided for frontline professionals • Rolling programme of ReSPECT training. 	<p>Appropriate application and use of DNACPR as needed</p>

<p>Care coordination: most cases showed absence of care coordination.</p>	<ul style="list-style-type: none"> • More patients with complex health issues having a named lead or care coordinator. • More people referred for End of life care; more patients participating in advanced end of life care planning so that their wishes are known in advance. • Regular feedback to acute and community around good and bad practices, using case studies to encourage discussions and closer working relationships between professionals. • Consistency in care assessments and their implementation - timely assessments and action taken to ensure changing needs are captured and addressed. 	<p>Evidence of smooth transition of care. -Named care coordinator especially for patients with complex needs.</p>
<p>Obesity and weight management</p>	<ul style="list-style-type: none"> • More personalised approach in managing patients who are clinically overweight and obese. • Action plans to be completed after every AHC to ensure those who are obese come away with a plan to address their weight which can also be monitored closely by the GP. • Dieticians to work more closely with GPs to discuss alternative ways of weight management, sharing information on what works and does not work. • Care staff to be trained on risks of poor nutrition including malnutrition and being underweight. • Obesity pathway, working group, to be set up to provide more education and guidance to carers supporting individuals in the community. • Improve the use of MCA. • Champions network for Nutrition and Hydration in place to support social care providers. 	<p>-Better outcomes from referrals. -LD tailored services with support. -Improved quality of life and wellbeing</p>
<p>Poor communication: some reviews showed evidence of poor communication between professionals themselves and families/ carers.</p>	<ul style="list-style-type: none"> • Promote sharing of information across services. Encourage health and social care teams to foster good communications between teams and families. • Encourage professionals to ensure appropriate clear language is used with families and carers and to be sure of their understanding before key decisions are made. • Encourage regular conversations take place to keep the families and carers involved with care and treatment. • Use of hospital passports or coordinate my care plan (CMC) to be encouraged. Carers/ families to ensure patients bring hospital passports when visiting health and social care services. Professionals to ensure these documents are regularly updated and used when an individual is admitted. • Keeping accurate and fit for purpose patients' record across all professional 	<p>-More meaningful family and carer engagement. -Evidence of improved patient and carers' experience</p>

<p>Lack of evidence recorded of care assessments and reviews within social care providers: there was no evidence recorded of regular social care reviews; carers and MCA in some reviews</p>	<ul style="list-style-type: none"> • Work with social care colleagues and providers to improve data collection for the reviews leading to demonstrating: • Improved mental capacity assessments on all learning disability patients deemed to lack capacity • Increased use of Independent mental capacity advocates (IMCA) to support patients with key making decisions (such as DNACPR, treatment procedures, finances and personal care), in line with the Mental Capacity Act. • More regular social care reviews to ensure changing patient needs are captured and acted upon in a timely manner. • Carers are provided with the right information and support to understand the importance of carers' assessments. • More joined up approach to supporting individuals, families and carers. Professionals to work closely together to identify and support carers before they hit crisis point. 	<p>More evidence of all-inclusive approach in the development of care packages that represent patient's needs -More social care assessments (MCA and carers) and applications of patient's best interest in all decision-making processes.</p>
<p>Recognising deterioration / End of life care- Some care staff were noted as not being able to identify deteriorating patients and advanced care planning referrals were delayed.</p>	<ul style="list-style-type: none"> • End of life pathway, working group to be set up to provide more education and guidance to carers supporting individuals. • More training on the needs of people with learning disabilities, including end of life training, to be provided to care staff to ensure they can recognise deterioration, and provide good quality care and better support to patients' when they get to end of life stage. • More staff awareness about deaths and supporting carers to have this discussion • More discussions with patients, carers and families on advanced care planning for deteriorating patients • More end-of-life information to be made available to patients, care providers and families to help them make informed decisions. • More awareness about the role of community learning disability teams and how to access them to provide support and ensure people with learning disabilities are able to access services they need 	<p>-More patients referred to EoL care services in a timely matter and have a comfortable end of life care. -improved family/ carer engagement and support -better understanding of LD needs</p>
<p>Inappropriate Hospital discharges. There was evidence of several failed discharges and re-</p>	<ul style="list-style-type: none"> • Improved discharge planning and a more coordinated approach involving families and carers and relevant community teams and GP practices. • Acute LD teams to work closely with CLDT teams and the social care teams on discharge process. 	<p>-Effective and Continuity of care outside the hospital. -Family/carer engagement in this process.</p>

admitted within less than 2 days.	<ul style="list-style-type: none">• Discharge information to be clearly explained to patient/families and carers and copies provided to GP practices, CDLT team and care homes in a timely way to ensure continuity and appropriate care.• Change of medication to be shared with GPs in a timely manner to ensure carers can arrange for prescriptions.	
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10. Local Priorities - Going Forward

The Learning from lives and deaths - People with a learning disability and autistic people (LeDeR) Programme in Norfolk and Waveney Plan 2021 to 2024 -2025

This is a working plan that will be updated once the new Integrated Care Board (ICB) and Integrated Care System (ICS) governance processes have been finalised. The plan will be agreed at the Learning Disability and Autism Programme Board to then be signed off until then the intention of the Norfolk and Waveney System is set out below:

10.1 Moving towards an Integrated Care Board

Norfolk and Waveney Integrated Care Board (ICB) will come into effect from 1 July 2022. To support the move from a Clinical Commissioning Group to an ICB, new governance structures are being finalised to support LeDeR delivery across the system. This has included recruitment to permanent reviewers and senior reviewers, new LeDeR panels and steering group, creation of a learning disabilities clinical champion post and new reporting mechanisms for learning and system change throughout the ICB.

10.2 Working in partnership

The Norfolk and Waveney system plan to deliver these changes over the next 3 years. Individuals with a learning disability and/or autism and their families and carers, are integral to this process of change.

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

Please contact us via these links:-

nwccg.haveyoursay@nhs.net

[Facebook](#)

[Twitter](#)

10.3 What we will do next?

This is our plan for acting on the learning that has come out of the reviews we have carried out in Norfolk and Waveney.

We have identified 16 areas that we need to work on over the next 3 years to improve health outcomes for persons with a learning disability and/or autism. These comprise:

- a. We will improve application of the Mental Capacity Act across our partner organisations. We will take steps to maximise choice, to maximise capacity, to ensure clear best interests decision making is evidenced where appropriate, and to make better use of advocacy services.
- b. We will make better use of annual health checks. We will increase uptake across Norfolk and Waveney, with a focus on improved quality and effectiveness of annual health checks, and we will ensure fair access to routine health screening and vaccinations. We will work to ensure GP registers of persons with a learning disability and/or autism are kept accurate and up to date.
- c. We will develop and embed increased knowledge and understanding of best practice in primary care networks. This will include a 'Learning disability Champion Forum' to share training, best practice, reasonable adjustments and expert advice to support primary care. This will also make available resources to support primary care in meeting the needs of individuals with a learning disability and/or autism
- d. We will improve our systems for the management of, and response to, instances where individuals 'Did Not Attend' (DNA) or Were Not Brought to, health care appointments. We will ensure missed appointments are actively followed up, we will ensure the reasons behind this are fully explored, and we will take steps to ensure health needs do not 'slip through the net'.
- e. We will ensure RESPECT and DNACPR forms are always completed comprehensively. We will take steps to ensure these documents are completed in full consultation with all relevant parties, including family and carers where appropriate and possible.
- f. We will work to improve the continuity of care when transitioning between primary and secondary care services and children to adult services. We will make better use of health passports, we will improve information exchange between services, we will ensure guidance on person-centred care moves with the individual across their care pathways.
- g. We will meet the health needs of those from an ethnic minority background with a learning disability and/or autism. We will gain a better understanding of the needs, and demographics of these communities. We will explore approaches to outreach and engage with all parts of our community.
- h. We will review the role of health facilitation and acute liaison services across Norfolk and Waveney. We will look at both the model used and the resources available. We will look to ensure a consistent approach and offer the same across our locations, in order to deliver best outcomes for individuals with a learning disability and/or autism.
- i. We will increase the understanding of subtle signs of deterioration with the role out of RESTORE2 mini across Norfolk and Waveney.
- j. We will promote system learning. We will explore ways to ensure that learning from death and examples of best practice are shared across health, social care and third sector services, rather than sitting in silos. We will learn together rather than in isolation. This will include regular feedback learning from LeDeR to primary care.

- k. We will define and establish a working local model of care coordination. We will look at both the model used and the resources available. We will look to ensure consistency of approach and offer across our location, in order to deliver best outcomes for individuals with a learning disability and/or autism.
- l. We will scope and review the range and availability of specialist community learning disability resources across Norfolk and Waveney. We will look at how they link in with other services and ensure a joined-up approach.
- m. We will explore better ways of engaging with individuals with learning disabilities and/or autism by listening to their feedback and using reasonable adjustments and use of virtual access (where appropriate) to ensure uptake of health appointments.
- n. We will ensure consistent access to end-of-life care in Norfolk and Waveney. We will take steps to ensure end of life services are meeting the needs of individuals with a learning disability and/or autism and will work with our hospices and other end of life services toward this end.
- o. We will promote physical health needs of individuals with learning disabilities and/or autism to ensure prompt responses to any subtle signs of physical deterioration.
- p. We will look for gaps in services where individuals with learning disabilities and/or autism have no input from healthcare and other relevant professionals. We will look for an approach where the individual has some professional oversight to ensure we are meeting their needs.

10.4 Next steps

The three-year plan will be completed for the Norfolk and Waveney system. We will work collaboratively to scope out a plan to meet the needs of individuals with learning disabilities and/or autism. This will be based on the priorities outlined and looking at innovative and creative ways to deliver a more robust model of care. The LeDeR steering group will help to inform this work.

11. Conclusion

We have been unable to make direct comparisons between the previous 2019-2020 report and this report due to changes in data recording on the national LeDeR system.

The year 2021-2022 saw the continuation of a challenging time for people with learning disabilities and we reported 13 deaths from COVID-19.

The median age of death for people with learning disabilities is 59 a year less than the national average and has reduced by 2 years in Norfolk and Waveney. We want to improve this by the service improvement priorities mentioned within the report.

We have collected data on our ethnic minority groups but will work to improve our recording to inform our practice.

We have seen improvements across the population of people with learning disabilities in having their annual health check something we wish to continue to promote and ensure all people with a learning disability from the age of 14 find a benefit to their long-term health and wellbeing.

We will improve the service provision for all people with learning disabilities and/or autism across health and social care in light of learning from the LeDeR reviews and in recognition of learning from the Norfolk 'Safeguarding Adult Review, Joanna, Jon and Ben'.

We value the expertise that the Experts with Lived Experience provide to both our LeDeR steering group and Learning into Action group.

It is important to remember each death reported was a person from our community and it is vital that we continue to improve the services we provide.

12. Appendix 1

Training Provided to social care (next year data will have specific to those caring for people with LD&A)

Learning session/ Champion	Date
Infection Prevention and control - COVID-19 (train the trainer) (Face to face/ virtual)	Multiple sessions
PBS Equipped certification	
Champion: Dignity	20/09/2019
Champion: Nutrition & Hydration	01/10/2019 29/01/2020 29/09/2020 10/03/2021 20/07/2021
Champion: Safeguarding	21/01/2020 24/06/2020
Infection Prevention and control - Winter resilience	02/10/2020 20/10/2020 17/11/2020 15/12/2020
Champion: Oral health	02/12/2020 16/06/2021 23/11/2021
Catheter Management (Registered staff)	03/08/2021
Catheter Management (Unregistered staff)	05/08/2021
Restore 2 mini (train the trainer)	17/08/2021 20/08/2021 17/11/2021
Bite size Skin part 1	06/10/2021
Bite size Skin part 2	20/10/2021
Bite size End of Life / ReSPECT	03/11/2021
Bite size Falls	01/12/2021
Nutrition & Hydration (LD specific)	02/12/2021
Nutrition & Hydration (non-LD)	07/12/2021
Pain Management	26/01/2022
Bite size Constipation	02/02/2022
Communicating health concerns effectively on behalf of your patients/residents	16/02/2022
Caring for those with Long-Term Breathlessness	02/03/2022
Bite size Dementia	23/03/2022
Epilepsy (<i>upcoming</i>)	27/04/2022
Accountability & Record keeping (<i>upcoming</i>)	04/05/2022
Medicines management (<i>upcoming</i>)	16/05/2022
Epilepsy (<i>upcoming</i>)	28/09/2022

Upcoming sessions		
Epilepsy Booking link: https://forms.office.com/r/Kexu2pkx1B		28/09/2022

13. Glossary of Terms

Arterial disease

A condition or illness related to the blood vessels such as the arteries.

Asthma

Asthma is caused by swelling (inflammation) of the breathing tubes that carry air in and out of the lungs. This makes the tubes highly sensitive, so they temporarily narrow. An exacerbation may occur randomly or after exposure to a trigger. Common asthma triggers include: allergies, smoke, exercise or infections.

Autism Spectrum Disorder

Autism is a spectrum of disorders which can have a wide-ranging impact on day-to-day life. This can include difficulties with social interaction and communication, processing delays, repetitive compulsions, and hypersensitivity to stimulus.

Bowel Obstruction

This is periods problem where your intestines (bowel) cannot move digested food through the body. This can either be because something is blocking the bowel, or the bowel isn't working properly.

Cardiovascular

This is the system which moves bloods around the body including the heart and blood vessels.

Cardiac arrest

A cardiac arrest is when your heart suddenly stops pumping blood around your body. This can have multiple causes.

Cerebral Palsy

This is the name for a group of lifelong conditions that effect movement and co-ordination, caused by a problem with the brain before, during or soon after birth. It can also include a range of other problems including swallowing difficulties and learning disabilities. The severity of problems in an individual can vary significantly.

Constipation

Constipation is a common condition which can make it difficult to have a poo. It is simple to treat but can be harmful if not managed.

Co-morbidities

This is where a person has more than one condition or disease.

Congenital Conditions

This is a disease or a syndrome which has been present since the person was born.

Diabetes

Diabetes is a lifelong condition that causes a person's blood sugar level to become too high. There are two types. Type 1 is caused by the body attacking the part of the body which makes a hormone called insulin. Type 1 is treated by lifelong insulin injections. Type 2 is when the body doesn't produce enough insulin, or the body doesn't use insulin well. Type 2 can be managed through healthy eating, regular exercise and achieving a healthy body weight, but may also need medication.

Dementia

Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of brain functioning. Dementia can impact memory, the way a person speaks, thinks, feels, and behaves.

Diagnostic Overshadowing

Diagnostic overshadowing occurs when a health professional assumes that a person with learning disabilities' behaviour is a part of their disability without exploring other factors such as illness or disease.

Dyslexia

Dyslexia is a learning difficulty (not a learning disability) which causes problems with reading, writing, and spelling.

Dysphagia

A difficulty is swallowing which requires a specialised feeding regime to avoid food and/or fluid entering the lungs (aspiration).

Endometrial cancer

A cancer in the lining of the womb.

Epilepsy

Epilepsy is a common condition that affects the brain and causes frequent seizures. Seizures are bursts of electrical activity in the brain that temporarily affect how it works. They can cause a wide range of symptoms.

Epilim

The brand name for Sodium Valproate, a medicine mainly used to treat epilepsy.

Frailty

Frailty refers to a person's mental and physical resilience, or their ability to bounce back and recover from events like illness and injury.

Heart Failure

This is a condition where your heart does not function properly to pump enough blood around the body. This can with be sudden (acute) or get progressively worse due to a long-term condition.

Impaired mobility

Where a person's ability to move freely and easily is made more difficult by their condition or age.

Influenza Vaccine

A vaccine to help prevent flu for those most at risk of serious complications.

Learning Disability

A learning disability affects the way a person understands information and how they communicate. This means they can have difficulty in understanding new or complex information, learning new skills and living independently. A Learning Disability can be Mild, Moderate, Severe or Profound depending on the severity and impact on day-to-day life.

Organ failure

This is a condition where an organ in your body does not function properly. This can with be sudden (acute) or get progressively worse due to a long-term condition. This may refer to one organ or a lot of organs (multi organ failure)

Pneumonia

Pneumonia is swelling of the tissue in one or both lungs. It's usually caused by a bacterial infection but can also be caused by a virus.

Aspiration Pneumonia

An infection in the lungs which is caused by the inhalation of liquid.

Pneumococcal Vaccination

A vaccine to help prevent pneumonia for those most at risk of serious complications.

Postural Kyphosis

A curvature of the spine which impacts posture and height.

Progressive Degenerative Illness

This is a disease or syndrome which will get worse as time goes on, with symptoms becoming more apparent and potentially harder to manage.

Renal

Meaning the kidneys.

Respiratory Failure

This is a condition where your lungs do not function properly to breathe in oxygen and breathe out carbon dioxide. This can with be sudden (acute) or get progressively worse due to a long-term condition.

Sepsis

Sepsis is a life-threatening reaction to an infection. It happens when your immune system overreacts to an infection and starts to damage your body's own tissues and organs.

SUDEP

Sudden Unexpected Death in Epilepsy is a known complication of epilepsy, especially when the seizures are not well controlled.

Urinary Tract Infections

This is an infection in the system which makes you urinate. Including the bladder, urethra, and kidneys.

14. Glossary of Acronyms

AHC: Annual Health Checks

Everyone over the age of 14 who has a learning disability is eligible for an annual health check. An annual health check can help you stay well by talking to a doctor or nurse about your health and finding any problems early, so they can be sorted out.

BMI: Body Mass Index

This is a calculator which determines whether a person is at a healthy weight. It considers different variables including height, weight, age, sex, ethnic origin and how much exercise someone does per week.

CCG: Clinical Commissioning Group

CCGs commission (find and pay for) most of the hospital and community NHS services in the local areas for which they are responsible.

CDOP: Child Death Overview Panel

A multi-agency panel set up by CDR partners to review the deaths of all children in their area, to learn lessons and share any findings for the prevention of future deaths.

CDR: Child Death Review

A national process to review the deaths of any person under the age of 18 years old

CLDT: Community Learning Disability Teams

An NHS services who work outside of the hospital to support adults with learning disabilities. They include health and social care professionals.

CMC: Coordinate My Care Plan

This is an NHS service that coordinates urgent care for patients. It includes diagnosis, medical details, resuscitation status, medications and recommendations for the urgent care services to follow in an emergency. Once completed the plan is

visible to all the urgent care services including 111, out of hours GPs, the ambulance (in their vehicles) and the emergency departments.

CPR: Cardiopulmonary Resuscitation

This is an emergency treatment for someone when they have stopped breathing and/or their heart has stopped beating properly. It is to keep oxygen going into their lungs and blood moving through their body.

DoLs: Deprivation of Liberty safeguards

These are checks which are part of the Mental Capacity Act 2005. It protects a person whose freedom might be limited by the care they are receiving making sure it is appropriate and is in their best interests.

DNA: Did Not Attend

A term used to describe when someone does not attend for an appointment.

DNACPR: Do Not Attempt Cardio-pulmonary Resuscitation

DNACPR means if your heart or breathing stops your healthcare team will not try to restart it. It is a decision made by you and/or your doctor or healthcare team.

ICB: Integrated Care Board

This is a governing body, as part of the ICS which allocated an NHS budget, commissions services and makes strategic plans for service changes and improvements.

ICS: Integrated Care System

These are geographically based partnerships that bring together health and social care providers and commissioners of NHS services with local authorities and other local partners to plan, co-ordinate and commission health and care services.

GP: General Practitioner

GPs treat all common medical conditions and refer patients to hospitals and other medical services for urgent and specialist treatment. They focus on the health of the whole person combining physical, psychological and social aspects of care.

IMCA: Independent Mental Capacity Advocate

An IMCA is an advocate appointed to support a person does not have the capacity to make certain decisions. This is a protected right under the Mental Capacity Act 2005.

LAC: Local Area Co-ordinator

A role which is part of the LeDeR process mainly responsible for governance, confirming reviews are of good quality with suitable recommendations and review allocation.

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

LeDeR is a service improvement programme which aims to improve care, reduce health inequalities and prevent premature mortality of people with a learning disability and autistic people by reviewing information about the health and social care support people received.

LD: Learning Disability

See glossary of terms

LD&A: Learning Disability and Autism

See glossary of terms

MCA: Mental Capacity Act

The Mental Capacity Act 2005 is an Act of the Parliament of the United Kingdom applying to England and Wales. Its primary purpose is to provide a legal framework for acting and making decisions on behalf of adults who lack the capacity to make particular decisions for themselves.

MDT: Multi-disciplinary Team

A group of different health and social care professionals who come together for a particular purpose.

NECSU: North of England Commissioning Support Unit

A service the CCG commissions to support with LeDeR reviews.

NHS: National Health Service

The National Health Service is the publicly funded healthcare system in England, and one of the four National Health Service systems in the United Kingdom.

NHSEI: National Health Service England and Improvement

NHSEI is an organisation dedicated to improving care for patients and providing leadership and support to the wider NHS.

NICE: National Institute for Health and Care Excellence

NICE is a public body of the Department of Health and Social Care which publishes guidance for best practice in health and social care.

NSAB: Norfolk Safeguarding Adults Board

NSAB is a group bringing together statutory and non-statutory organisations to address the issue of abuse and harm.

N&W: Norfolk and Waveney

The geographical area covered by the CCG authoring this report.

NWCCG: Norfolk and Waveney Clinical Commissioning Group

As above

PCN: Primary Care Network

A PCN is a structure to help GP practices work together with community, mental health, social care, pharmacy, hospital and voluntary services.

ReSPECT: Recommended Summary Plan for Emergency Care and Treatment documentation

The ReSPECT process creates a summary of personalised recommendations for a person's clinical care in a future emergency in which they do not have capacity to make or express choices.

SALT: Speech and Language Therapy

Speech and language therapy provides treatment, support and care for people who have difficulties with communication, or with eating, drinking and swallowing.

SAR: Safeguarding Adults Review

A SAR is a Multi-Agency review process which looks at what agencies and individuals involved could have done differently that could have prevented harm or a death from taking place.

SJR: Structured Judgement Review

An SJR is a review process for when a person with an LD dies in hospital. It is used to find any potentially avoidable deaths in hospitals and understand and learn from failures in care.

SRO: Senior Responsible Officer

An SRO is in charge and responsible for making sure a programme or project does what it is meant to do.

STOMP: Stopping overmedication of people with a learning disability

STOMP is a national project to stop the overuse of psychotropic medicines. Psychotropic medicines affect how the brain works and include medicines for psychosis, depression, anxiety, sleep problems, epilepsy and sometimes for behaviour which is seen as challenging.

WTE: Whole Time Equivalent

Used to describe the workload of someone working part time hours in comparison to a full time employed person