



Lincolnshire
Integrated Care Board

Learning from Lives and Deaths (LeDeR) in Lincolnshire

Annual Report 2024



This report is dedicated to the memory of

Ethan Patrick McCauley

25/07/2002 - 06/11/2024

Executive Summary

Learning from lives and deaths - people with a learning disability and autistic people (LeDeR) is a service improvement programme funded by NHS England which aims to improve services for people with a learning disability and autistic people. LeDeR shows that people with a learning disability and autistic people die earlier on average than other people, and do not always receive the same quality of care. [NHS England Action from learning report 2022/23](#)

The Annual LeDeR Report for Lincolnshire 2024 will share the findings and learning from LeDeR Reviews undertaken throughout the year and will report upon the ways in which the Lincolnshire Integrated Care System is delivering on local actions, highlighting the work that was undertaken throughout the past year, including activities and achievements in alignment with the 6 Regional High Impact Actions. We will also outline some of the planning looking forward into 2025 as we continue to improve services and the health and lives of people with a learning disability and autistic people in Lincolnshire.

Regular updates and feedback from the LeDeR Programme are reported to the following groups across Lincolnshire ICB/ICS;

- Learning Disability Partnership Board (LAPPB) – Quarterly meetings
- Transforming Care Partnership Board (TCPB) – Monthly meetings
- LeDeR Governance Panel - Bimonthly meetings and ad hoc extra-ordinary meetings
- Nursing and Quality Meeting – Monthly meetings

Introduction

Our Vision, Aims and Objectives for the LeDeR programme in Lincolnshire;

Our purpose and aspirations are firmly rooted in seeing a reduction in early mortality for people with a learning disability and autistic people in Lincolnshire.

We will do this by;

- Positively influencing people, providers, teams and organisations who impact upon the lives of people with a learning disability and autistic people.
- Continuation of our pursuit of the improvement in the quality of health services across the county working in collaboration with our partners across the different sectors to ensure the delivery of training and awareness of the need to reduce health inequalities for people with a learning disability and autistic people.
- Ensuring that our learning outcomes and recommended improvements from LeDeR reviews continue to be driven forward by the Governance Panel, actions disseminated timely and followed up smartly.



Notifications and Reviews

Adult Notifications Received this Year	61
Reviews Allocated this Year	65
Reviews Signed Off this Year	53
CDOP Reviews in Progress	5
Median Age of Death	65
Early Deaths (<65)	75%

What the data is telling us

Notifications received

There were 62 adult notifications received in Lincolnshire between January 2024 and November 2024. A **DECREASE** of 7 from 2023.



Notifications allocated

62 notifications were allocated for initial or focussed review during the year.



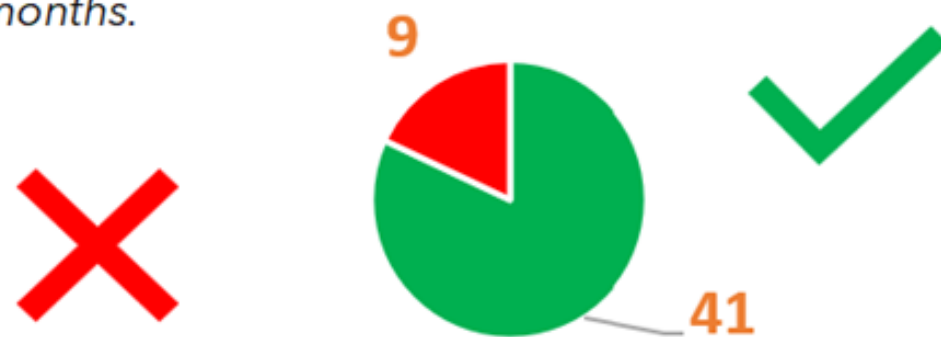
Reviews completed

There were 50 reviews completed and signed off in the year. That is an **INCREASE** of 3 from the previous year.



Reviews completed within 6 months

82% of reviews signed off between January 2024 and November 2024 were completed within 6 months.



Reasons for 6-month breaches

The most common reasons for the 6-month time limit on reviews being completed in Lincolnshire for 2024 were:

1. Allocated 3 months following notification due to reviewer capacity
2. Allocated 2 months following notification due to reviewer capacity



Child reviews

There were 5 child reviews received during the year, 7% of the total notifications. A **INCREASE** of 2 reviews from 2023



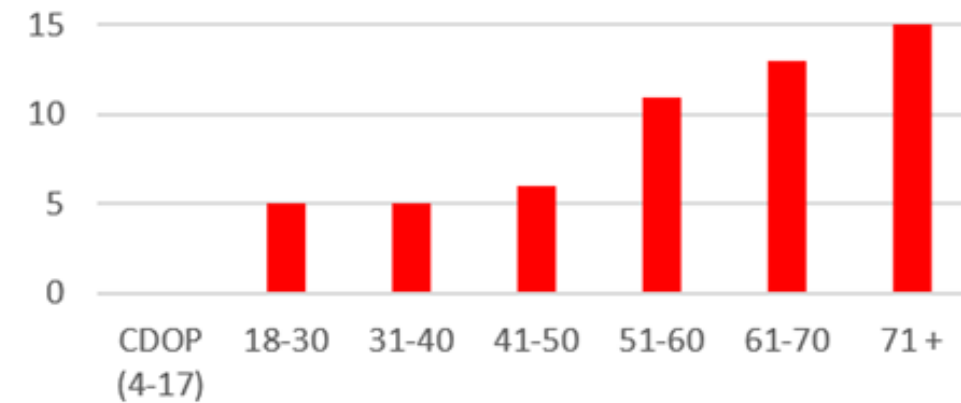
What the data is telling us

Sex

56% of people in the Lincolnshire data who died in 2024 were male and 44% female.



Age



Age at death

The median age of death for people with a Learning Disability or Autism was 65. The average life expectancy for the general Lincolnshire population is 81.

65 Years

Diagnosis

50 of LeDeR reviews in 2024 were for patients diagnosed with a LD (81%). The remaining 15% were diagnosed with a LD & Autism.



Ethnicity

100% of people who died in 2024 in Lincolnshire identified as "White British".

100%

Early death

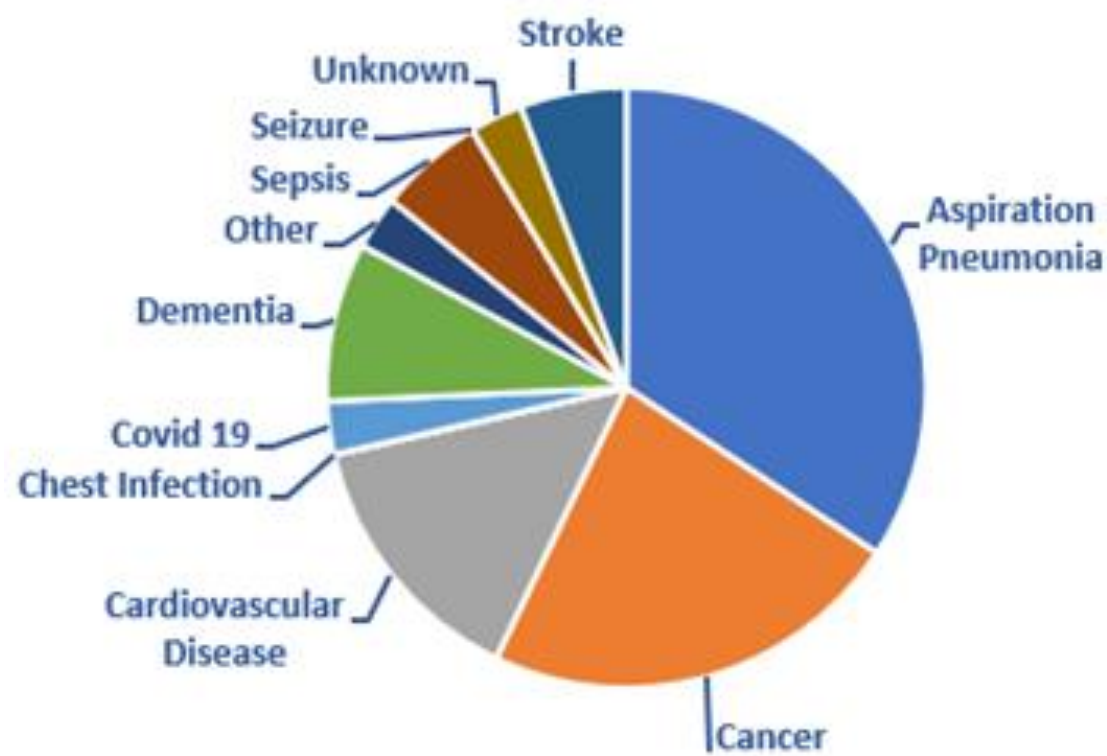
More than 6 out of 10 of those who died in Lincolnshire with a LD and/or Autism died before they were 65. This compares to around 1 out of 10 in the general population.



What the data is telling us

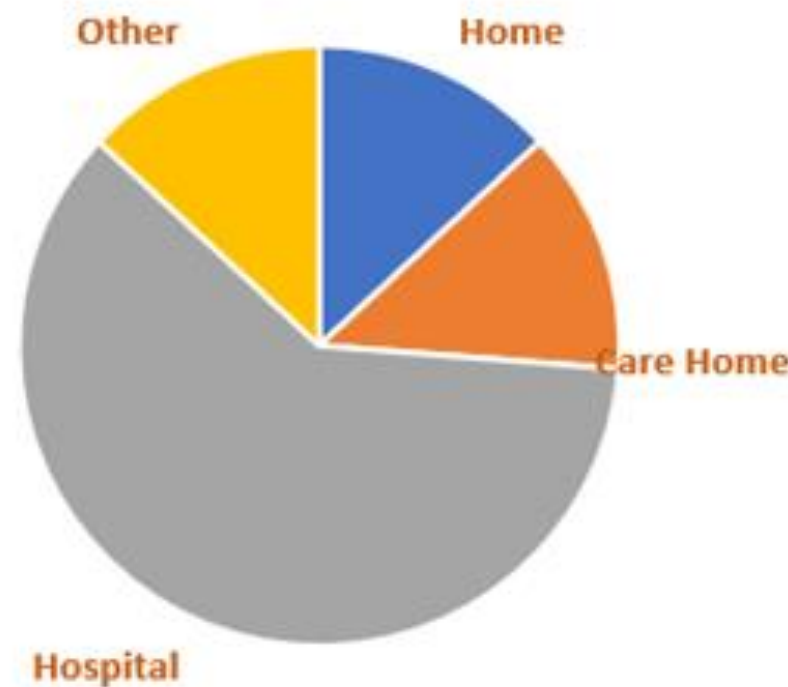
Cause of death

The top 3 causes of death for people diagnosed with a Learning Disability and/or autism in Lincolnshire were Aspiration Pneumonia, Cancer and Cardiovascular Disease.



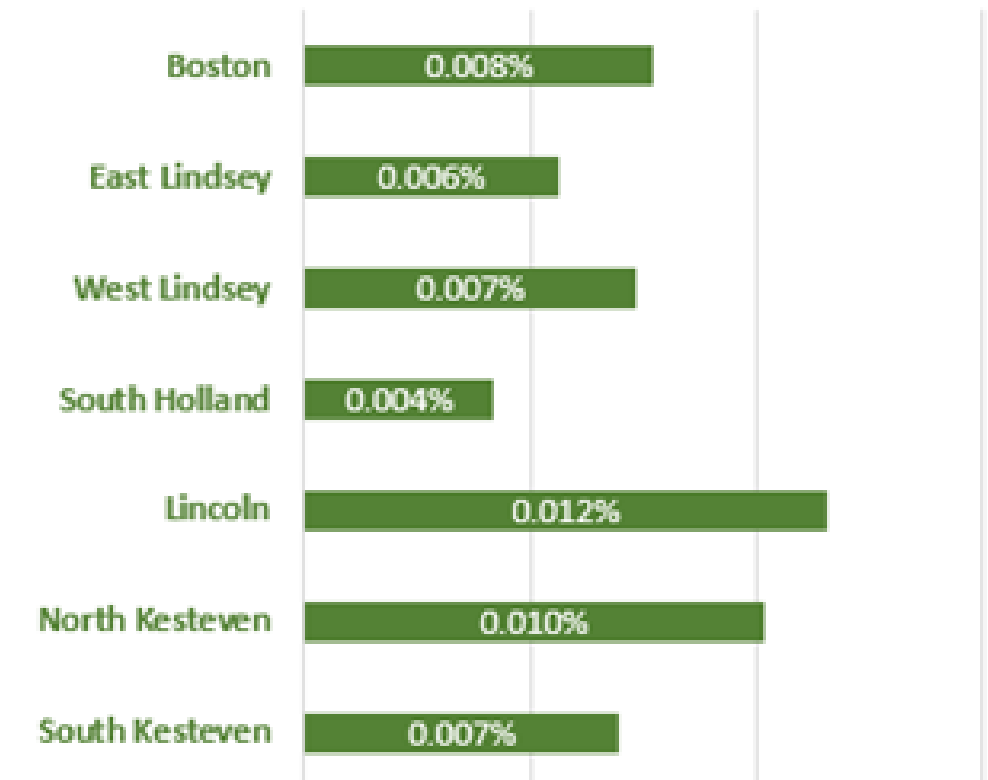
Place of death

61% of deaths occurred in a hospital setting. An **INCREASE** of 10% from 2023. Deaths in a care home setting **DECREASED** from 25% in 2023 to 13% in 2024.



Lincolnshire districts

The 2 highest percentage of deaths per population in Lincolnshire were North Kesteven and Lincoln, more than double that of some districts.



Aspiration Pneumonia, Cardiovascular Disease and cancer continue to be the highest cause of deaths in 2024. Therefore, we continue to include these three causes of death in our local criteria for focussed reviews and for presentation to the Governance Panel to identify actions for learning.

Lincolnshire Joined Intelligence Dataset

The following analysis uses data from the Lincolnshire Joined Intelligence Dataset. This dataset collates data from general practice, acute service providers, community service providers, mental health service providers, adult social care, and other wider determinants of health data. Readers should interpret these findings with caution, as there are known data quality issues which may provide misleading results.

Between August 2023 and July 2024 in Lincolnshire:

- People with a learning disability had on average 4 community healthcare encounters. Those without a learning disability had on average 1.2 community healthcare encounters.
- People with a learning disability had on average 43.6 encounters with their GP. Those without a learning disability had on average 26.0 encounters with their GP.
- People with a learning disability had on average 0.4 encounters with mental health services. Those without a learning disability had on average 3.9 encounters with mental health services.
- 0.8% (42/5039) of people with a learning disability had a new recording of alcohol abuse on their medical records. 1.1% (8949/813874) of people without a learning disability had a new recording of alcohol abuse on their medical records.
- 6.9% (349/5039) of people with a learning disability had a recording of smoking on their medical records. 5.6% (45833/813874) of people without a learning disability had a recording of smoking on their medical record.
- 1.6% (80/5039) of people with a learning disability had a recording of vaping on their medical records. 0.5% (3822/813874) of people without a learning disability had a recording of vaping on their medical records.

Lincolnshire ICS Joined Intelligence Dataset, NHS Lincolnshire ICB December 2024.

Comparison of people in Lincolnshire with and without a learning disability and long-term conditions

The following table shows the difference in prevalence of the following physical and mental health conditions marked on health records between August 2023 and July 2024 for Lincolnshire citizens with and without a learning disability:

Health condition	People with a learning disability	People without a learning disability
Anxiety	24.1% (1217/5039)	17.7% (144276/813847)
Asthma (QOF definition)	9.5% (481/5039)	7.1% (57893/813874)
Atrial Fibrillation	1.5% (76/4039)	3.3% (26498/813874)
Autism Spectrum Disorder	34.9% (1760/5039)	1.4% (11524/813874)
Chronic Kidney Disease	4.4% (9224/5039)	6.4% (52434/813874)
COPD	1.4% (71/5039)	2.8% (922681/813874)
Depression	17.1% (860/5039)	17.8% (144680/813874)
Diabetes	7.9% (398/5039)	7.2% (58409/813874)
Epilepsy	21.7% (1093/5039)	1.2% (9859/813874)
Hypertension	12.6% (636/5039)	19.3% (157226/813874)
Obesity	34.4% (1731/5039)	19.4% (158490/813874)
Has ever attempted to commit suicide	31.6% (1592/5039)	2.0% (16571/813874)
On at least one routine waiting list	14.8% (746/5039)	10.9% (88956/813874)
On at least one urgent waiting list	5.3% (115/5039)	1.9% (15457/813874)

Lincolnshire ICS Joined Intelligence Dataset, NHS Lincolnshire ICB December 2024.

Diabetes 8 Care Processes – Learning Disability Population compared to the non-learning disability population

Managing diabetes effectively requires a comprehensive and proactive approach to healthcare. Both type 1 and type 2 diabetes are chronic conditions that can lead to serious complications if not properly monitored and managed. To mitigate risks associated with unchecked diabetes, the NHS have established a set of eight care processes.

Blood pressure management, BMI measurement, and smoking status recording processes all have higher completion rates in the learning disability population for Lincolnshire. This may be because people with a learning disability have an annual physical health check, at which these processes are completed. Those who do not have a learning disability may not have as much interaction with the health service.

8 care processes (reporting period: 01/11/23 to 31/10/24)	People with a learning disability	People without a learning disability
HbA1c measurement	89.6% (353/394)	91.9% (51364/55901)
Blood Pressure Measurement	91.4% (360/394)	88.4% (49389/55901)
Cholesterol Measurement	83.5% (329/394)	85.4% (47817/55901)
Serum Creatinine Measurement (Kidney Function Test)	89.1% (351/394)	90.9% (50813/55901)
Urine Albumin Creatinine Ratio (ACR) Measurement	52.3% (206/394)	61.9% (34602/55901)
Foot examination	62.4% (246/394)	69.7% (38951/55901)
BMI Measurement	80.7% (318/394)	78.7% 43986/55901
Smoking Status recorded	90.4% (356/394)	82.2% 45947/55901
All 8 care processes received	36.5% (144/394)	46.2% 25837/55901

Lincolnshire ICS Joined Intelligence Dataset, NHS Lincolnshire ICB December 2024.

Addressing Health Inequalities

The LeDeR Team continue to work in collaboration with the Lincolnshire NHS ICB Health Inequalities Team to ensure there is a clear link between our target population cohort in LeDeR and the Lincolnshire PLUS groups. PLUS groups are population groups which experience poorer than average health access, experience and/or outcomes across their communities, and form part of the [Core20PLUS5 approach](#).

The list of PLUS groups for Lincolnshire is as follows;

- People from ethnic minority backgrounds
- People from Eastern European backgrounds
- People with a learning disability
- People with a severe mental illness
- People with autism or neurodiversity
- Gypsy, Roma, and Traveler communities
- People experiencing homelessness
- People who are carers
- People with sensory impairments
- Temporary residents
- Military Personnel, their families and Veterans
- People from rural and/or coastal communities

These groups are included in the criteria nationally and / or locally and meet the scoping for a focused LeDeR review.

These groups will be added to our data set to ensure we capture patterns and trends borne out of additional and wider determinants of health to address health inequalities in Lincolnshire.

Cancer a top priority in 2023/24

The LeDeR Governance Board identified cancer as being a top priority in 2023/24

Cancer was one of the four top causes of death for people diagnosed with a learning disability and/or autism in Lincolnshire in 2022/23 and has remained one of the top causes of death in 2023/24.

Where we need to be

Reduction of LeDeR notifications as the cause of death being cancer where there was no screening, diagnosis and treatment plan.

How are we going to do it?

- Continue to promote the importance of Annual Health Checks and screening for people with a learning disability and autistic people.
- Continue to work in collaboration across the ICB and ICS supporting local workstreams and projects to reduce health inequalities.
- Continue to deliver interactive and educational workshops across the sectors to promote awareness of the correlation between learning disability and higher rates of cancer to encourage higher levels of uptake in NHS cancer screening programmes.



The Lincolnshire Cancer Summit 2024 Cancer and Learning Disabilities Workshop

The Senior LeDeR Team in Lincolnshire were excited to have been asked to present a workshop at the 2024 Cancer Summit which was held on Wednesday 12th June 2024 at The University of Lincoln Medical School.

The theme of the Cancer Summit 2024 was health inequalities. Eight different workshops explored inequalities at different points on cancer pathways for different cohorts of patients, demonstrating system wide inequalities impacting upon people living with cancer.

The NHS Lincolnshire ICB senior LeDeR team produced a workshop; “ Learning from Lives and Deaths (LeDeR) Service Improvement Programme – A focus upon Cancer and People with Learning Disabilities.



The Lincolnshire Cancer Summit 2024 Cancer and Learning Disabilities Workshop

The Workshop aims were to provide attendee's with:

Awareness and understanding of the LeDeR programme and the vision for a reduction in the frequency of deaths that were potentially avoidable or responsive to good quality healthcare.

Understanding of how patient outcomes and quality of life can be improved because of shifting the care pathway from a suboptimal journey to one that consistently delivered timely care at the right time by the right services with the focus upon Lorraine Abbott EbE telling her story of a person who has lived experience of LD and cancer.

Understanding of why it is important to ensure people with a LD have the same access to cancer screening as the rest of the population.

Knowledge of programmes of care and schemes around the county which promote good healthcare for people with LD i.e., Annual LD Health checks and LD Friendly GP Practice accreditation programme.



Cancer and Learning Disabilities Webinar - 9th October 2024

NHS Lincolnshire ICB co-produced a Webinar on 9th October 2024 to promote equal access to screening to avoid missed opportunities and reduce health inequalities for Lincolnshire citizens who have a learning disability and autistic people.

With a real-life story, we explored the ways in which we can ensure that we are promoting equitable access to cancer services and local cancer pathways for people with a learning disability, with appropriate recognition of any additional needs and Reasonable Adjustments that are required, and to ensure that opportunities for screening, diagnosing, care and treatment are not missed throughout the patient's journey.

We had some great speakers on the day including Ruth Willis Macmillan Strategic Partnership Manager, who shared some insights and learning from some of the engagement activity that has taken place in the Midlands, and examples of work, good practices, resources and materials.

Macmillan Clinical Nurse Specialist Leanne Fahy joined us from a local perspective in Lincs highlighting the No Barriers Here Project. Leanne is also one of our LeDeR Reviewers here in Lincolnshire.

Cath Koutna, NHSLICB Cancer Project Manager, and James Allen NHSLICB Health Inequalities Improvement Facilitator shared their work on a local Cancer Bowel screening project; Improving the uptake of Bowel Cancer Screening for people with Learning Disabilities.

Person Profile: Lorraine Abbott - Expert by Experience

My name is Lorraine Abbott. I am employed by NHS LICB as an Expert by Experience with lived experience of a learning disability.

My main role within the MHLDA Team is to sit on Care and Treatment Review Panels for our patients with a learning disability.

I speak up for myself, and others with learning disabilities who cannot speak up for themselves, who have a right to be heard.

I enjoy helping to inform any changes that need to happen with their care and treatment. I am particularly passionate about the importance of everyone with a learning disability being on their GP Practice's LD Register and being offered required adjustments to attend their Annual Health Checks every year.

I have had good and bad experiences with my own and enjoy sharing my own experiences to make things better. I believe in equality in health and social care, for everyone, and that is what my job is all about.

Lorraine has been supporting with webinars and projects this year.



Lorraine's Story

"Hi my name is Lorraine Abbott. I am a mother of a son who is 40 this year. I have Learning Disabilities and Dysexecutive Syndrome and I am employed by NHS Lincolnshire as an Expert by Experience."

October 2014

"I felt really ill, being sick and losing weight."

"I was scared, I did not know what was wrong with me."

"I went to my GP around 30 times, because I was feeling very unwell. Every time they took my bloods but didn't explain why. All I knew was that I wasn't getting any better."

"I wasn't on my GP LD Register and so did not receive annual health checks."

"I had to stop my cleaning job because I was so ill. I spent 3 months not knowing what was wrong with me and feeling really unwell."

"I had to cancel my holiday to my sons over Christmas 2014 and when he visited me in January 2015, he was shocked at how much weight I had lost."

Lorraine's Story

“The next Sunday I started to throw up blood. I was scared. I rang 111 and they told me to go to the nearest hospital. It was 5am on Sunday morning and told them I had no way of getting to hospital. They told me to go to the local Urgent Care Clinic at my GP surgery, so I arrived there at 8am to be told to come back the next day. When I attended the GP the next day, I collapsed. They took more bloods and told me I need to be admitted to hospital.”

“Nobody told me what was happening. I wasn't told anything. I felt like a number NOT like a very sick person with feelings. At hospital I had an endoscopy which showed I had a badly ulcerated stomach. Further explorations diagnosed me with Non-Hodgkin's Lymphoma.”

“I was traumatised and so scared, not knowing what was happening, or why. At least now I knew what was wrong with me.”

“How would you have felt in my situation, not knowing what was wrong with you, whether you will get better, or any of the how, what, where, and whys?”

“I can tell you it was terrifying, and I can still remember all of it, vividly and don't ever want to feel helpless, scared, like a number, ever again.”

Lorraine's Story

“Once I was diagnosed with cancer, believe it or not, my experience got so much better.”

“I was supported by my LD Liaison Nurse, and Macmillan Nurses. They made sure I understood what was wrong, and what my treatment was going to look and feel like.”

“They gave me accessible information about cancer and my treatment and were with me every step of the way. Knowledge is power and I felt much better when I understood everything that was going to happen. I was not scared anymore because I knew what to expect.”

“I spent 3 months in hospital having chemotherapy via two needles, one in my hand, and one in my back. I also underwent lots of scans and more blood tests, but I didn't mind because I understood what they were for.”

April 2015

“I transferred to a residential home for people with Learning Disabilities, a lot of whom I knew. This felt more homely as I continued my chemotherapy for another 6 months. I did return to hospital once due to an infection. I felt looked after and cared for and I understood what the treatment was doing. I was supported to attend my consultant's appointment at QMC and left elated. I was told the treatment had worked and I could go home. The residential home threw a celebration for me before I went home.”

Lorraine's Story

"I was glad to finally be home in my own familiar surroundings. I continued to receive support from the LD Liaison Nurse and quickly felt my old self again. I had regularly check-ups for the next 3 years. When I was told I was finally and completely cancer free, I was so happy and relieved. I felt grateful for the great care I received in hospital and at the residential home. Life is less stressful when you understand what is going on."

"I will forever be grateful for the Liaison LD Nurse and Macmillan Nurses who made my hospital stay much more patient centred, but most importantly, made sure I understood what was wrong with me, and how my treatment would feel, how long it would last, and the end goal."

"I now work for NHS Lincolnshire ICB as an Expert by Experience (EbE) and support patients at their Care and Treatment Reviews. I believe everyone has the right to the same care and treatment no matter what your abilities, age, race etc."

Lorraine's Story

Lorraine's take away message;

"Talk to us we don't bite!"

"We may need things delivered in a slightly different way."

"Look at the person, not just the diagnosis, operation, procedure."

"Check we understand."

"I want to make sure no-one has to feel the way I did back in 2014/2015."

Whilst watching the video and listening to Lorraine's story, attendees were asked to jot down some "quick wins" in response to how things could have been improved for Lorraine at the investigative and diagnostic stage.

We then had three break out rooms to reflect upon Lorraine's story and bring our thoughts back to the wider group.

Learning Objective

By listening to Lorraine's Story, we gained an understanding of how patient outcomes and quality of life can be improved by adapting the care pathway to one that consistently delivers timely care at the right time by the right services.

Below are a few of the insights we captured from the breakout rooms.

Issues;

- Lack of communication
- Became more isolated
- Missing a holistic approach
- Lack of reasonable adjustments
- Concerns about weight
- No advocacy
- Felt scared and frightened
- 111 call handling advice – not appropriate / no reasonable adjustments



Quick wins;

- 111 call handling training
- GP training – ensure the LD section is ticked at diagnostic stage
- Rephrasing of medical terms
- Nominated / named practitioner from the GP Practice
- Referrals to LD team at screening stage
- Library of resources to be made accessible
- Hospital passwords, All About Me to be made available for Primary Care.
- LD Register to be regularly validated

ICB Bowel Cancer Screening Project

The NHS Lincolnshire ICB Health Inequalities Programme is leading a Bowel Cancer Screening Project with the support of the ICB Cancer Team and Dr Nicholas Bigwood who completed a GP fellowship on Deprivation.

The project is focused on the 4 most deprived GP practices of Lincolnshire in Skegness, Mablethorpe & Gainsborough. The project aims to understand the barriers which prevent people in these areas from taking part in the national bowel cancer screening programme. As part of the project, a workstream was launched to address the number of people with a learning disability in care homes and the community in these areas who are eligible to take part in the screening programme, but that do not.

This focused piece of work is to support an increased uptake in the bowel cancer screening programme for people with a learning disability. This in part is supported by the creation of a resource document which will be introduced into care homes, to support staff who are caring for people that are eligible to take part in the bowel screening programme. Additionally, NHS Lincolnshire ICB Expert by Experience Lorraine Abbot has supported the project by taking part in a bowel screening instructional video for people with learning disabilities.



Respiratory Disease

Respiratory disease is one of the biggest causes of death for people with a learning disability in England but many of these deaths are avoidable. In 2021 over 50% of people with a learning disability died before they were 65 years old compared to about 1 in 10 of the general population (LeDeR Annual report 2021).

Aspiration Pneumonia is the top cause of death of people in Lincolnshire who are diagnosed with a Learning disability, it being responsible for 18% of all deaths in the last 12 months equating to 6 out of 34 reported deaths for the period.



Respiratory Disease

The Complex Needs Rapid Response Respiratory Service Lincolnshire Community Health Trust (LCHS) provides specialist assessment, treatment and management of children and adults of all ages with complex physical disabilities with additional respiratory problems in the community.

The aims of the service are to:

- Provide higher standard of clinical treatment and improved outcomes for children and adults with long term conditions
- Reduce hospital admissions, length of stay, readmissions and the number of A&E attendances
- Improve children, adults and their families/carers experience of using services by building on the existing integrated models to join up care between community services, acute services and palliative care services
- Proactively target children and adults at risk of acute respiratory infections early to help keep them healthy and prevent acute infections in the first instance

The Team shared an example of the work they do in Lincolnshire. Ethan is a young man who has a chronic lung condition and lots of other complex health issues. Ethan's Mum, Celia has given NHSLICB permission to share their story.



[Watch video](#)

NHS Lincolnshire ICB hosted and co-presented an Aspiration Pneumonia Webinar on the 8th May in 2024.

The aim of the webinar was to raise awareness and provide advice on aspiration pneumonia and learning disability.

The Workshop Activity was based upon the story of Robert, a fictional patient, to show the difference between a suboptimal (undesirable with negative outcomes), but realistic, pathway of care compared to an optimal (best practice with good outcomes) pathway of care.

Our guest speaker was Hannah Borrill, Specialist Physiotherapist with The Complex Needs Rapid Response Respiratory Service Lincolnshire Community Health Trust (LCHS).

Hannah delivered a presentation on the following;

- What is aspiration pneumonia
- What makes our service users/patients vulnerable to aspiration
- Identifying signs and symptoms of chest problems
- Services available support an unwell patient and role of respiratory physiotherapy



ReSPECT Webinar 16th January 2024

ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment.

The LeDeR Governance Board in Lincolnshire identified ReSPECT / DNACPR as a local key priority for 2023/24. In collecting rich data from LeDeR Reviews we captured insights to identify patterns, trends and inconsistencies in the application and use of ReSPECT / DNAR across the county.

A ReSPECT Webinar took place on 16th January 2024, reaching out across residential, nursing home, community supported living providers, Day Care provisions, NHS Trust provider teams and Primary Care Teams. Jenny Fryer, NHS Lincolnshire ICB Project Development Manager Enhanced Health in Care Homes and ReSPECT delivered a presentation of how the ReSPECT process has been adopted throughout Lincolnshire.

The desired outcome of ongoing learning in this area is for Lincolnshire citizens who have learning disabilities and/or autistic people to have the opportunity to voice their wishes and choices or be supported to make decisions about emergency treatment and end of life care.



Assuring and Sustaining Performance

The LeDeR programme in Lincolnshire has formulated and deployed a recovery plan in response to our LeDeR Performance rates and falling below the desired 100% of proportion of reviews completed within 6 months of notification (6 month rolling period).

The recovery plan is taking good effect to date;

Aims; improve the Key Performance Indicator (KPI) for 6-month Completion of reviews.

- Increase the number of NHS Lincolnshire system reviewers – Bank hours have been approved and a retired nurse who is an experienced LeDeR Reviewer has joined us for x16 hours per week on a bank contract. 11 reviews with GP records received have been allocated and has reduced our backlog to 7 reviews as of December.
- Advertise/Publicise for LeDeR reviewers both internally and across the health system - Expressions of interest received from LCC and ULHT, meet and greets and introductions to the programme in situ with potential reviewers, two individuals registered for the e-learning prior to allocation of reviews.
- Governance Panels are held bi-monthly and in addition there have been 4 extra-ordinary governance panels held between June and October 2024 to mitigate delays in focused reviews are not delayed in being signed off.
- NHS LICB MHLDA LeDeR Reviewers are also Case Managers. All Case Managers have been stepped down from Duty case manager roles and are protecting that time for dedicated LeDeR work.

Assuring and Sustaining Performance

Jodie Goodman, Senior LeDeR Reviewer and Rachel O'Halloran, LeDeR Reviewer from the Lincolnshire LeDeR Team participated in the Peer Review on 9th July 2024. Here are some of their observations;

“It was interesting to hear how other areas work in terms of quality assuring reviews and sign off at governance panel. We are all doing it slightly differently and our process (Lincolnshire) feels a lot tighter than others.”

“Good networking opportunity with other reviewers and Local Area Contacts. Opportunity to share ideas.”

“My only criticism would be that the review chosen for our area was one from before LeDeR sat with the MHLDA Team and was a review that was completed by an external company. Detail was lacking and poorly completed with a lot of inaccuracies. For future involvement in peer review work, we feel it would be better to present a review that we were the reviewers in terms of quality assurance and sign off.”

A Local Project – Working Together

In Lincolnshire in 2022/23, 81.2% of people aged 14 years and over with a learning disability on the GP register received an annual health check (3373 out of 4155). (PHE Fingertips2024).

Lincolnshire County Council Day Care Service Virginia House are undertaking a project with a Lincolnshire GP Practice.

Debbie Dennis, Day Centre Manager told us,

“It originally started with the original figures from the questionnaire that was sent to everyone after Covid , where we were looking at the quality of annual health checks , not the quantity, and where it highlighted that people were not attending or being offered to people. The outcome of the original figures was that as a service we all need to work together to get it right and identify what reasonable adjustments need to be implemented to make this happen for people with a disability.”



A Local Project – Working Together

- Working in partnership with local PCN, parents/carers and adult day services (Virginia House)
- The purpose being to promote individuals with learning disabilities the right to equality in health care
- We are in the first stages of this project, having held one initial meeting explaining what we want the outcomes to be:
 - For individuals to be able to access annual health checks in a comfortable environment, including the day service, home etc.
 - To gather data to improve choice and uptake of health services for our individuals
 - To ensure a personal approach to healthcare
- Progress so far
 - Regular visits from the LD nurse to Virginia House
 - LD nurse coming into Virginia House, working with one individual who was reluctant to access health services. Leading to referrals to relevant specialist services.
 - Good communication links are in the process of being established
 - Adaptions and reasonable adjustments becoming more readily identified



A Local Project – Working Together

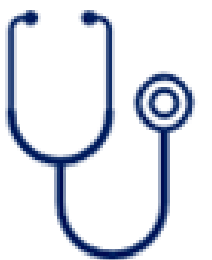
1st Step – We designed a questionnaire to find out from parents and carers of the individuals who access our service if annual health checks were being offered. Also, if so the quality of them.

THESE ARE THE QUESTIONS WE ASKED PARENTS AND CARERS

- Have you had an annual health check in the last year ?
- How did your GP practice contact you and invite you for a check ?
- How did you find the experience of booking an appointment for the annual health check ?
- Was the time suitable?
- What information did you receive before the health check ?
- Was it in a format that was easy to read and understand?
- What was your experience like going for your annual health check ?



- Was the location convenient and did you require support?
- What was the experience like at your annual health check?
- Did the professional communicate with the person?
- Was the professional knowledgeable and did they understand learning disabilities?
- What happened at the end of the annual health check ?
- Was there a follow up or a health action plan completed ?
- Did you get any advice and information?
- What could improve?
- Did reasonable adjustments need to be put in place ?
- Any other comments



A Local Project – Working Together

Model of Delivery

We have been working with PCN to improve the uptake of annual health checks, through offering our day service facilities as a familiar environment for our individuals to access their checks.

We have access to other equipment that may enable better outcomes for the individual such as wheelchair weighing scales and have provided this data to the GP surgeries

One of our local LD nurses has been into the day service to pilot this model with one individual who was difficult to interact with through family.

A Local Project – Working Together

Outcomes of Pilot

The pilot Annual Health Check at our service identified several health concerns that we were able to be acted upon.

Highlighted the importance of working in partnership with our local PCN.

Highlighted the need for different ways of communicating the need for medical screening, such as easy read pamphlets and being offered the checks in a way that is understood by the individuals' and their families.

For our PCN to attend regular parent/carer meetings to discuss concerns and ways to move forward with regards to the health care of their loved ones.

Moving forward, the LD Nurse is moving this pilot out to the rest of our individuals who access our day service.

A Local Project – Working Together

Dawn Skelland-Thornton, PCN Manager and Digital Transformation Lead with Meridian Medical PCN, told us;

“We have been working closely with Virginia House on this pilot health check project.”

“Dr Parkes and the team have been out several times now to discuss the project with the day centre Manager Debbie Dennis, who gave us the approval to go ahead.”

“She gave us a list of patients attending the day care centre and to start with, we are concentrating on patients from East Lindsey Medical Group and James Street Family Practice as there were also a number from other PCN’s.”

“We then had a morning meet and greet with Dr Parkes and the HCA’s (Health Care Assistants) with the patients and parents/guardians/carers. This gave them further confidence in the project and are all now happy for the team to proceed.”

A Local Project – Working Together

“We worked through the LD review that they would normally do in practice, to ensure that all parameters would be covered to ensure a thorough health check. They will be covering BP, weight, smoking/alcohol status, medication review, Ethnicity, Immunisations and where relevant, bowel, breast or cervical screening and checking when last offered etc, when last bloods done etc. Also ensuring that they’ve had the correct education and leaflets.”

“Our next step is to arrange for our HCA’s from ELMG to arrange for the health checks to take place, so we are working with them and the day centre, to arrange the appointments.”

“We are working closely with the team for baseline data and then hopefully we’ll be able to move forward from there and make improvements. We have coded the specific patients as attending the day centre and we’ll compare with the general population of LD patients.”

“Next steps: we would also do a satisfaction questionnaire for patient /guardian /carer – this is still to be planned.”

B died of Community Acquired Pneumonia.

B was 26yrs of age. He had a diagnosis of severe learning disability, epilepsy, and cerebral palsy. He attended a Special School and received respite also.

B communicated with smiles and sometimes a nod or cry. It was necessary to anticipate his needs. He reached out frequently for tactile gratification. His mother described him as the most amazing young man who only became irritable when he was ill and stopped eating. On 4th September 2023 B was presented at the GP as increasingly breathless. This was reported as a difficult examination but no respiratory concerns, commenced a 5-day course of oral amoxicillin and GP advised 999 if he deteriorated.

On 6th September he was seen in A&E, he presented as increasingly breathless, off diet and fluids and with oedema to his feet. Initial ReSPECT form was completed, reflective of active treatment and records reflected a conversation had with B's mother.

On 6th September B's care was discussed with consultant and nurse in charge. Plan was made for end-of-life care and anticipatory medications. Review indicated likely aspiration pneumonia, and a syringe driver was commenced with Midazolam, Oxycodone and Alfentanil. B was transferred to MEAU on 07/09/23. B's family were called to his bedside and at 00.45 and it was confirmed that he had passed away.

Action From Learning from Focussed Reviews - A local focused review presented to Governance Panel

Issue: GP should have made a referral to urology for investigation and management, gap in services due to B having recurrent UTI's. The conversation in relation to RESPECT does not appear to have been handled sensitively. There was misunderstanding re epilepsy medication and dosages. The family did not feel listened to and did not expect their son to die. They have received no aftercare.

Learning: Following the correct pathways for recurrent UTI S. LD physical health nurses could have been key in supporting those investigations in terms of reasonable adjustments needed. LD liaison nurse made a referral on the 13th December 2019 to the physical health nurse, however the GP advised that the service was not commissioned to complete a general or more specific review. Clarity needed around what the referral was for.

Actions Agreed at Panel: Physical Health Liaison Lead, Adult Learning Disability Service to seek clarity on what the referral was for. Named GP for Safeguarding Children and Adults, NHS Lincolnshire Integrated Care Board to feedback to GPs, either in general via a letter or to the identified GP practice. Sensitivity required when having difficult conversations/discussions with families. Specialist Safeguarding Learning Disability Nurse, ULHT to feedback to A&E/MEAU.

Positive Practice: When B attended A&E he was supported by the Acute Learning Disability Liaison Nurse, who attended on each admission and provided supportive care plans.

M died of Metastatic cancer of unknown primary

M was a 55-year-old man who lived his whole life in Lincolnshire. He was described as a lovely, amenable man who's 'life changed' when he moved into supported living in 2019. His supported accommodation didn't exist prior to M needing it, the service manager had run a day centre and provided support in people's homes (including to M and his dad), but when M needed somewhere to live, it inspired her to change her service provision to accommodate him.

M had several long-term health conditions - asthma, autism, a mild learning disability, schizophrenia, some incontinence and osteoarthritis in his left thumb.

M needed a small amount of prompting and guidance around some activities of daily living and help with more complex decision making. M's schizophrenia was stable and carer's who worked with him over 12 years, reported seeing no overt symptoms of this until his antipsychotic medication was stopped.

Action From Learning from Focussed Reviews - A local focused review presented to Governance Panel

Issues: A Respect form was not available on reviewing M's GP records. Nor was there any evidence that a RESPECT conversation has taken place. Inconsistent staff attended to M at his GP surgery. The above impacted on continuity, view of the condition and accumulation of concerns, communication and therapeutic relationships between M, his care team, and the GP surgery. ADL needs were not met efficiently or consistently on the ward including nutritional intake and personal care. The LDA All About Me bundle was not completed, and staff kept losing the hospital passport brought in by care staff on more than one occasion. It is not clear any reasonable adjustments were discussed or applied. There appeared to be a clear push for discharge from hospital despite symptoms ongoing and carers and family voicing concern.

Learning: Training needs for GPs around reasonable adjustments and the need where practically possible for consistency. Primary Care to be encouraged to complete the ReSPECT e Learning package.

Actions agreed at Governance Panel: The LD Disability Care Bundle to be reviewed and revised with emphasis on it being done with the patient and the carers and family (this has been completed). A recent GP forum about LeDeR Reviews has taken place, some of the LeDeR cases have been highlighted along with some of the learning. The Oliver McGowan training will be rolling out in primary care again.

Acknowledging Good Practice and feed back to teams: M was cared for deeply by his community care provider, they had known M for over 12 years and treated him as close to family as possible. M's life changed when he moved to his new accommodation. It is reported that M's carers had found the LD community team helpful and supportive, with good communication and a holistic approach.

T died of Intestinal Blockage leading to Aspirational Pneumonia and Sepsis.

T was a 49-year-old quadriplegic lady with diagnoses of cerebral palsy, severe learning disability, scoliosis and well controlled epilepsy. T was fed by a PEG, suffered with heavy periods and constipation. From the age of 10 T lived with foster parents and attended a specialist residential school before moving into a community placement. Due to a deterioration in her physical health T was placed in nursing home however subsequently moved to a residential home.

T had a good sense of humour, enjoyed listening to music, watching TV and sensory lights, sitting in the garden and loved having her hair done. T always had a smile on her face and reacted positively to people who talked to her by maintaining eye contact. T relied on carers interpreting her body language and vocalisations to ensure her needs were met.

T attended for annual health checks however these were brief or incomplete. There was a clear record of reoccurring constipation, documented since 2006, with regular use of multiple laxatives and intermittent/as needed suppositories prescribed.

T lived at a new residential home for 6 weeks before passing away and had been struggling with bowel movements since arriving but there was no indicator she was becoming physically unwell until the day the GP was contacted. Medication was prescribed for severe constipation, and a manual evacuation was attempted. A few days later, following repeated vomiting, an ambulance was called and despite attempts to escalate it took 6 hours to arrive. On admission to A&E T was diagnosed with a bowel blockage and aspirational pneumonia. It was decided T was not suitable for surgical intervention and End of Life care was initiated.

Action From Learning from Focussed Reviews - A local focused review presented to Governance Panel

Issues: It was unclear that initial concerns around minimal bowel movements was managed appropriately during the lead up to death. No Care support worker able to go to hospital with T. Whilst the LD bundle is completed on the wards, there is no current provision of LD in A&E in Lincolnshire hospitals.

Learning: Care providers to be support and educated around best practice and ways to support this health concern. LD needs were not communicated to staff caring for T in hospital. The importance of bowel care and monitoring to be shared across the system.

Actions agreed at Governance Panel: Actions agreed at Governance Panel: The ICB to co-present a Webinar in 2025 to be based on Bowel Health and Constipation. Providers to ensure food & fluid intake and bowel movements are monitored. ICB and local authority to support providers of health and social care services to reduce the risk of Lincolnshire residents not being supported in A&E and that hypothetical discussions take place at the point of annual review and contingency documented in care records. For providers to ensure that all residents have a hospital passport/grab sheet/grab bag for all admissions and for these discussions to place during annual reviews.

Acknowledging Good Practice and feed back to teams: Her residential care home helped T feel like part of a family, they advocated for her and supported her during the lengthy delay in receiving care.

Positive Practices: Findings from initial reviews

“Perceived excellent standard of palliative care provided by community team and support to the supported living provider who provided the highest standard and dignity of end-of-life care.”

“M was cared for deeply by his community care provider, they had known M for over 12 years and treated him as close to family as possible. M’s life changed when he moved to his new accommodation.”

“Whilst he had a diagnosis of Alzheimer’s he was able to make some decisions himself, but there was evidence of MCA/BI for decisions that he was unable to make.”

“The individual received exemplary care before and during the diagnosis of cancer. All relevant professionals were informed and communicated well to provide the upmost care the later days of life. The care provider supported the individual for 5 years and increased their support hours to give palliative care. The individual was always made central to his care.”



Positive Practices: Findings from initial reviews

We feel it important to acknowledge good care and treatment and always write to the provider in recognition of positive practices identified from both initial and focused reviews.

Here is an excerpt taken from one of the letters we sent over the past 12 months;

“I am writing to you on behalf of the Lincolnshire LeDeR Team. LeDeR is also known as the Learning from Lives and Deaths programme.”

“We recently conducted a review of the life and death of the late A and on behalf of the LeDeR Governance Board would like to take the opportunity to acknowledge the outstanding care and support provided by your team as identified in the review.”

“Family was informed at every stage of A’s situation during his admission to hospital. K.....s Care Home communicated with family regularly and provided excellent care throughout A’s stay with them.”

“Please do not hesitate to contact us further with regards to this should you wish and please find attached some useful links to both information about the LeDeR programme both nationally and locally in Lincolnshire.”

Issue, concern or potential problems: Reviewers findings from initial reviews

“Only 1/5 references of capacity assessments appeared to follow the principles of the Mental Capacity Act, 2005.”

“Inconsistent staff attended to M at his GP surgery. This impacted on consistency, view of the condition and accumulation of concerns, communication and therapeutic relationships between M, his care team, and the GP surgery.”

“Push for discharge from hospital despite symptoms ongoing and carers and family voicing concern. Carer's are a key player in LDA service user's care and need to be seen with more significance in supporting them to communicate their needs.”

“Non-appointment attendance due to documented capacity issues, however not appropriately followed up or supported via best interest process.”

“No evidence in annual LD review or how the individual communicated despite family reporting they could use Makaton.”

“When staff at the placement requested an ambulance, the request was declined due to J not engaging with the GP and not letting him examine her. This should not be a reason not to attend to a person who is in pain and suffering.”



Mencap Treat Me Well

Hello my name is Michelle

I am a Speak Out Leader for VoiceAbility Lincolnshire, and I am also an Ambassador for Mencap's Treat Me Well program.



As an Ambassador I help with the campaign for reasonable adjustments.



This means working with people with a learning disability to make sure they are heard and get the right treatment.



Reasonable adjustments help people with disabilities to use health services.



Things like having accessible information, thinking about the time and environment or making small changes to appointments all help.



We are now working on promoting the flag system on files to identify different support needs.



This will help to make sure people get the right amount of time given to their appointments and allow for reasonable adjustments to be made.



I would like everyone to get good treatment.

Sensory friendly resource bags for patients with learning disabilities and autistic people

Sensory bags have been launched by ULHT as a pilot scheme and is funded by ULHT charities.

Patients with sensory needs often find emergency department environments overwhelming, due to all the noises and activity.

Sensory friendly resource bags are being made available at Lincoln, Boston and Grantham hospitals and are for all age patients with learning disabilities and autistic people who come into the Emergency Department.

The bags include items such as noise-reducing headphones, an eye mask, stress ball, a sensory chew bracelet and a colouring book with pencils. Each bag also contains an easy-read patient information leaflet and a feedback form to gather insights for continuous improvement.

Patients get to keep the bags with them, use on the ward if they become an inpatient and take them home with them for future use. An Easy Read Leaflet has been developed by ULHT to guide patients with the use of the sensory bags.

Sensory friendly resource bag for patients with learning disabilities and/or autism

If you are living with a Learning Disability and/or Autism and feel the bag would be of benefit, please speak to a member of the team

The bags contain items that will help reduce anxieties, sensory overload and enhance wellbeing



Learning Disability Bundle in ULHT

When a patient with learning disabilities is admitted to hospital, they should have a Learning Disability Bundle completed with them and or their family/ carers.

This bundle looks at the patients individual learning disability needs, communication needs and reasonable adjustments while in acute hospital environment. It can be completed by any of the staff on the ward and is an opportunity to explain and record the needs of the patient.

There is a flow chart at the start of mandatory actions to be completed by ward staff such as referral to Acute Learning Disability Liaison Nurse and adding alerts.

Alerts can be added to ULHT system to identify reasonable adjustment need for any future admissions. The bundle helps identify if patient requires any extra support on ward, such as one to one carer by ward staff or own carers and or family staying on ward to support. It's a supportive document which can be reviewed and change as care needs change during patient admission and discharge from acute hospital.



**United Lincolnshire
Hospitals**
NHS Trust



Looking ahead

The Epilepsy and LD Delivery Group aims to have the SUDEP risk checklist in every GP surgery and acute hospital setting in Lincolnshire by mid 2025 and have commissioned the services of SUDEP Action, to co-host a whole day on 10th February 2025, International Epilepsy Day, in Sleaford Lincolnshire. The plan is for SUDEP Action to present in the morning and for the delivery of workshops all afternoon. Feedback to be provided in Quarter One Report 2025.

Learning Disability Specialist Nurses at United Lincolnshire Hospitals Trust (ULHT) are currently working on a new version of the All About Me Hospital Passport as the existing one is over ten years old. NHS Lincolnshire ICB LD epilepsy work Programme have allocated funding to support the update of the All About Me Passport.

Feedback has been obtained from patients, carers groups, professionals from Lincolnshire Partnership NHS Trust and ULHT, both children and adults services, as well as Speak out Leaders from Voiceability and an Expert By Experience along with peer support workers from LPFT services.

Further updates to be provided in Quarter Reports once the work is completed and the new version is relaunched.

NHS Lincolnshire ICB will continue to co-produce quarterly webinars throughout 2025 in alignment with the objectives of the 6 regional High Impact Actions and in alignment with the findings and actions for learning from LeDeR Reviews.

April 2025 – Cardiovascular Disease Webinar

July – 2025 Bowel Health and constipation Webinar

A note from the Author

As the Local Area Contact for LeDeR, I would like to take the opportunity to thank my Co-Authors for their continuous clinical governance and data modelling to enable us to turn our findings into insights and identifying opportunities for improving services in Lincolnshire and without whom this report would not be possible;

Improvement & Delivery Managers and Senior LeDeR Reviewers: Jodie Goodman and Katrina Brown.

LeDeR Administrator: Suse Kilburn

Commissioning Officer: Skye Cooper

Thank You

The senior LeDeR team would like to thank the following people without whom the continuous learning from reviews and opportunity for service improvement would not be possible;

All our dedicated LeDeR Reviewers from across the Lincolnshire Integrated Care System for their commitment to improve services for people with a learning disability and autistic people.

The family members, friends and carers who at a time of bereavement have shared their stories of their loved ones with reviewers and who have agreed to reviews being shared to support learning and service improvement.

To our system partners, for providing the information to help us undertake the reviews, by responding to feedback and continuing to support the LeDeR Programme in Lincolnshire.

And

The Lincolnshire LeDeR Governance Board Panel for their ongoing commitment of panel meetings and continual support of the programme.

Credits and Acknowledgements

Thank you to all those who have contributed to this report by sharing their stories, projects and workstreams:

- Debbie Dennis, Virginia House Day Care Centre and Dawn Skelland-Thornton, The James Street Family Practice Louth
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- The Epilepsy and Learning Disability Working Group, NHS Lincolnshire
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- Kerry Gibson Speak out Leader and Michelle Ornstein Speak Out Facilitator, Voiceability Lincolnshire.

Conclusion

As we head into 2025 and continue to develop the LeDeR programme and our dataset in Lincolnshire, so do our opportunities for further statistical and thematic analysis to allow us to identify trends and develop valuable insights to understand where initiatives have been effective and target specific areas where more needs to be done in terms of service improvement.

We are constantly striving for opportunities in Lincolnshire to improve health outcomes for people with a learning disability, and autistic people and to reduce health inequalities.

We hope this report illustrates our shared vision and collective goal from across the Integrated Care System, working in true co-production to reach our outcome.

A handwritten signature in black ink that reads "Claire Frances". The signature is written in a cursive, flowing style.

Claire Frances
Senior Commissioning Manger for NHS Lincolnshire ICB
Local Area Contact for the LeDeR programme in Lincolnshire