



# Learning Disability and Autism Team Annual Report 2024-2025



## **Foreword**

Welcome to the fourth Annual Report from the Leeds Teaching Hospitals NHS Trust (LTHT) Learning Disability and Autism Team.

We would like to extend our gratitude to our partners for their ongoing collaboration in helping us ensure that patients with learning disabilities and autistic patients receive fair and equitable access to healthcare.

The primary focus of our team is to address health inequalities and enhance patient outcomes, and we are proud to share the progress we made towards this goal in 2024-2025.

## **Our Aim**

We are committed to improve the quality and experience of patient care within our hospitals. We will do this by drawing on substantial clinical expertise and the voice of people with lived experience of a learning disability and or Autism to instil a culture of continuous improvement.

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## **1. Introduction**

Welcome to our fourth annual report for Learning Disability and Autism at LTHT. The core value for learning disability and Autism at Leeds Teaching Hospitals is that all patients are treated as individuals and services make efforts to understand the patient alongside making reasonable adjustments so equitable access to healthcare is always offered and delivered.

Care should be delivered to meet the needs of the individual drawing on expertise from the patient, their carers and other professionals as required.

Meeting the needs of patients with a learning disability and or Autistic people is the responsibility of the whole organisation in line with the Health and Social Care Act 2012 and the Equality Act 2010

In its early years, the team focused primarily on direct patient support and bespoke amendments to pathways. This approach is evolving as we now emphasize workforce development, education, and strategic intervention across the entire organization. Our goal is to build a workforce capable of meeting the needs of our patient population, reducing but not eliminating the need for specialist services such as the Learning Disability and Autism Team to be present to ensure patients needs are met.

### **1.1 Learning Disability / Intellectual Disability (LD/ID)**

A learning disability is defined by the Department of Health and Social Care 2001 as “a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood”.

A learning disability is different for everyone. In all cases learning disability is a lifelong condition.

Learning disability and intellectual disability are interchangeable titles, and both mean the same. There are many other ways people may refer to a learning disability however these are the two accepted terms.

A learning disability is different to a learning difficulty, which is a reduced ability for a specific form of learning and includes conditions such as dyslexia (reading) dyspraxia (affecting physical coordination). A person with a learning disability may also have one or more learning difficulties.

### **1.2 Autism**

Autism is a lifelong condition which affects how people communicate and interact with the world. The definition of Autism has changed over decades and may change in future as we understand more about Autistic people. It is a spectrum condition and affects people in different ways. Like all people, Autistic people have their own strengths and weaknesses (Based on the definition from National Autistic Society)

## 2. Learning Disabilities and Autism: Current Drivers

Health drivers for learning disability and autism focus on improving outcomes, reducing inequalities, and ensuring equitable access to care. Key drivers include:

1. **Person-Centred Care:** Tailoring healthcare to individual needs.
2. **Reducing Health Inequalities:** Addressing health disparities and ensuring equal access to services.
3. **Early Intervention:** Promoting early identification and prevention.
4. **Workforce Development:** Training healthcare professionals to better support individuals.
5. **Accessibility:** Ensuring healthcare environments are inclusive and adaptable.
6. **Family and Carer Support:** Providing resources and education for families and carers.
7. **Integrated Care:** Coordinating services for comprehensive care.
8. **Advocacy and Rights:** Empowering individuals to have a voice in their care.
9. **Data and Research:** Monitoring outcomes and driving improvements through research.

The Learning Disability and Autism Team strategy for 2025-2028 is reflective of this. The drivers for individuals with Learning Disabilities and Autism remain consistent with established themes. National, regional, and local guidelines provide ongoing guidance, and the team often contributes to these documents and reviews. The Trust has dedicated workstreams to meet National Standards and ensure compliance, which is subsequently fed back through the Safeguarding Governance Group for assurance.

## 3. National and Local Context for Learning Disabilities and Autism

- Learning Disability and Autism Improvement Standards (2018)
- NHS Annual Benchmarking- Learning Disability and Autism
- Learning Disability Mortality Review Programme (LeDeR)
- The Accessible Information Standard (2016)
- The Equality Act (2010)
- National Autism Strategy (2021)
- The Long Term Plan for Learning Disability and Autism
- The Autism Act (2009)
- NICE guidance, as appropriate

## 4. Governance Arrangements for Learning Disability and Autism at Leeds Teaching Hospitals

The Chief Nurse is the Executive Lead for LD and Autism.

The Deputy Chief Nurse and the Head of Nursing Safeguarding, Mental Health Legislation, Learning Disabilities and Autism provide strategic direction for Learning Disability and Autism. They support the Chief Nurse in the Executive role.

The Lead Professional for LD and Autism provides the organisation with operational and strategic advice, support and input for this patient group. The LD and Autism Team professionals are committed to supporting the workforce in understanding the needs of patients with LD and Autism.

Governance groups provide challenge and assurance regarding the LD and Autism agenda within the Trust, monitor compliance and benchmarking with external standards and key clinical effectiveness indicators (including Care Quality Commission (CQC) outcomes), and report, advise and act on findings to address any gaps.



The Learning Disability and Autism Team also inputs into several working groups across LTHT:

- Learning Disability and Autism Reference Groups
- Training Lead Forum
- Clinical Effectiveness and Outcomes Group
- Health Inequality Groups
- Patient Information Forum
- Patient Experience Subgroup
- Quality Assurance Committee
- Trust Board

- Mortality Improvement Group
- Child Death Review Meeting

## **5. The Learning Disability and Autism Team overview**

The Learning Disability and Autism team sits within the Chief Nurse Clinical Service Unit and as such follows the governance and assurance arrangements in place within this structure.

We know from the LeDeR (Learning from the lives and deaths of people with a Learning Disability and Autistic people) review program (NHSE) that our population group are still at risk of dying prematurely. They suffer health inequalities on many levels, and it is our job as a provider to reduce these risks and inequalities to ultimately improve the lives of people with a learning disability and Autistic people.

The team is in place to support the growth and development of the Leeds Teaching Hospitals workforce. The service provided is a life span service across all areas of the organisation.

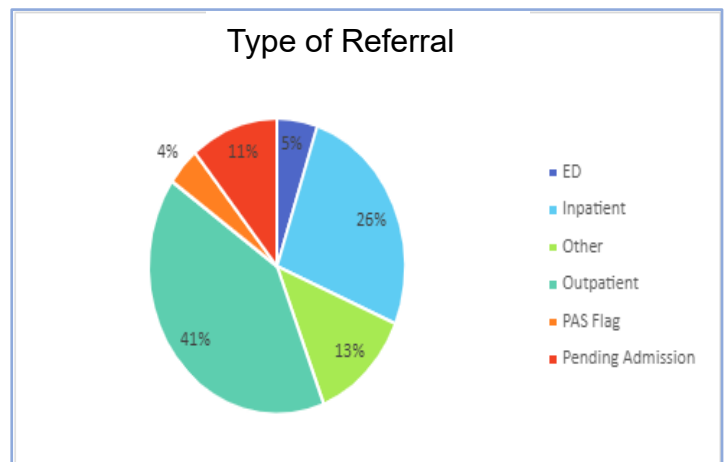
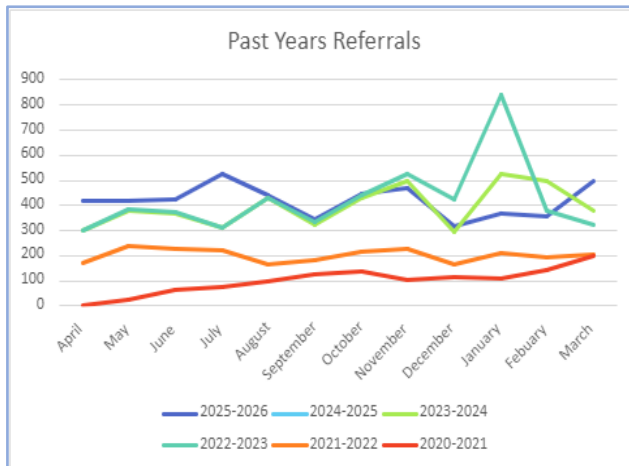
We promote a culture of continuous improvement with the patient at the forefront of all we do. The Learning Disability and Autism Team provide a service Monday to Friday. The key responsibilities of the service fit into three workstreams.

- Workforce Education - We work with the whole organisation to ensure there are effective ways to train healthcare staff to plan and deliver services that meet the needs of this patient population, in line with the Core Capabilities Frameworks for Learning Disabilities and Autism and Skills for Healthcare guidance.
- Quality Improvement - We work strategically to analyse our service highlighting risks and gaps in provision to target quality improvement initiatives, using the Leeds Improvement Method to embed real change.
- Clinical - A specialist provision to support clinical teams, external providers and individual patients on a need led basis looking at bespoke pieces of work to ensure patients have equitable access to healthcare.

Our service can only provide support to patients who have a diagnosis of learning disability or Autism. Patients who do not have a diagnosis, or are awaiting assessment, may still require reasonable adjustments. Teams can utilise the resources on our website to support good quality care.

This year we have supported 5015 patients in total.





This year 41% of our total patient support has been for patients attending outpatients, ensuring that reasonable adjustments were in place before they attended departments. Further enhancing our vision that the right provisions should be in place before a patient attends the Trust.

Additionally, 11% of our clinical work has been targeted towards patients with pending admissions, ensuring liaison work is completed in a timely manner and treating teams are educated and supported to ensure the right care is in place at time of admission.

### 5.1 The team also continue to lead or co-lead several programmes across the Trust

- Leads on the provision of Accessible Information Leaflets in line with the Accessible Information Standard.
- Leads on all assurance work related to Learning Disability and Autism (e.g. national benchmarking, local audit, NICE, mortality reviews).
- Leads/ supports a number of service improvement projects.
- Leads the development of adjusted pathways and is working towards a Learning Disability and Autism specific recommended pathway.
- Is delivering a training strategy for the LTHT workforce, including registered staff, unregistered staff and students.
- Leads on the strategic inclusion of people with living experience of Learning Disability and Autism at LTHT, with 8 Get Me Better Champions working as Experts by Experience and several Autistic people regularly contributing to the work of the Autism Subgroup.
- Leads or supports city wide/ regional work linked to the Leeds agendas for Learning Disabilities and Autism.
- Offers an MDT approach, with physiotherapy and RGN's in the workforce, in addition to the more established Acute Liaison RNLD role.
- Offers support to colleagues in all roles across the Trust.

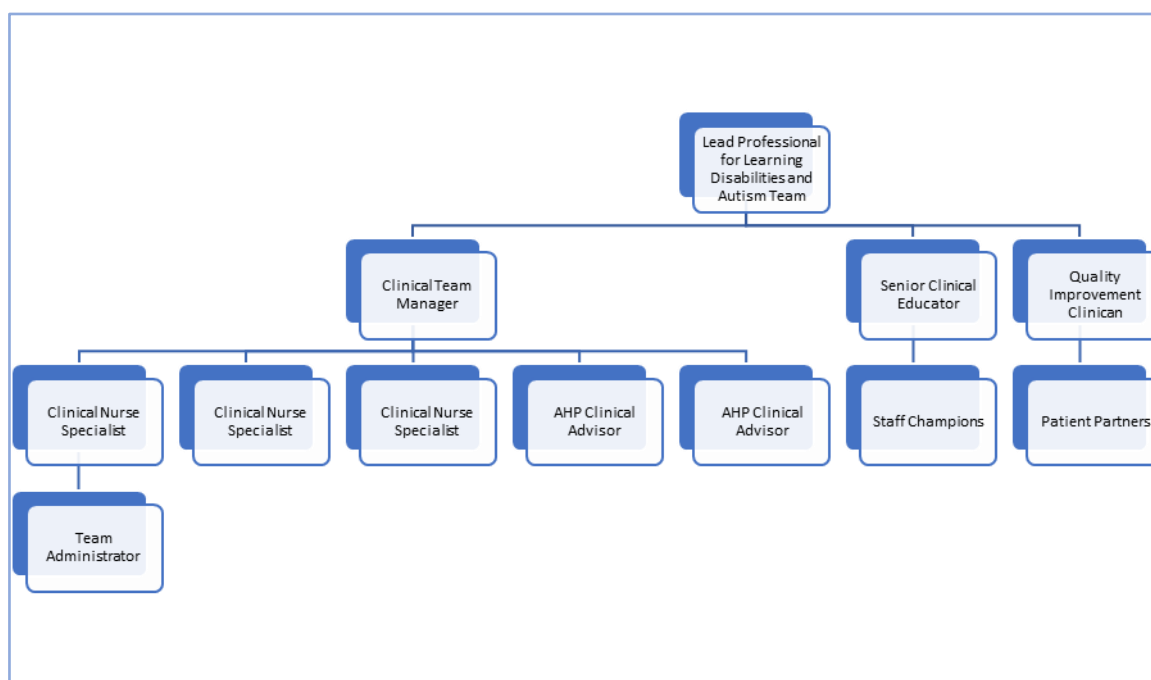
- Oversees all responses to PALS and Complaints for this patient group, ensuring reasonable adjustments are made in line with NHS England's Ask, Listen Do initiative.

## 5.2 Risks Associated with the Current Position

There is a recorded risk that Reasonable Adjustments are not made for people with a learning disability and/ or Autism. This risk has been recorded as a 12 for some time, however in November 2024 this risk was reduced to a 9 based on the current team structure. The team securing permanent funding and a reduction in staff turnover has allowed a period of stability which is reflected in the risk rating reduction.

There is a financial risk to the organisation related to the Oliver McGowan Training for Learning Disability and Autism. This is a new training programme for all health and social care, which is proposed to involve a full day plus e learning for all patient facing staff. Staff with no patient contact are likely to require e learning and a shorter learning burst. The final code of practice is awaited, however currently it appears that the cost for this training will be with providers.

The team has received £10,000 from the ICB to pay our Co Trainers with lived experience; however, this is a non-recurring payment. There is also additional funds shared across the West Yorkshire working group for the Oliver McGowan Training, this will support an external provider to begin delivering Tier 2 of the training from June 2025. Again, these funds are non-recurring, and the team will be seeking other financial support to ensure this standard is maintained over the coming financial year.



## 6. Key Celebrations and Achievements in 2024-2025

### 6.1 Champions Conference

This year the Learning Disability and Autism team held its first Staff Champions conference. The aim of the conference was to share knowledge and upskill staff who are already part of the Learning Disability and Autism Staff Champions programme. The agenda was formulated based on requests for bespoke training, themes from the Learning Disability Mortality Review Programme Report and our upcoming pieces of work.

The conference was attended by 33 delegates.



### 6.2 Learning Disabilities and Autism Awards 2024

In 2024 at the National Awards Conference the Learning Disabilities and Autism Team was shortlisted for the Breaking Down Barriers Award (Team). The service came in second place as highly commended for the work across the Trusts Urgent Care services and emergency departments, providing Care Bags to people with a learning disability and Autistic patients. The service was commended for “breaking down barriers” and “setting an example for other Trusts”. The Care Bag Scheme was also featured on ITV’s Calendar in November 2024.

**The Breaking Down Barriers Award (Team)**

**Winner: Access All Areas**

Access All Areas employs learning disabled and autistic individuals in TV and theatre. They provide training on accessibility and disability awareness to major UK companies, establishing industry standards. Their Transforming Leadership program and creative support team promote inclusive practices and are leading by example. Well done, keep up the good work.

**Highly Commended: Leeds Teaching Hospitals Trust Learning Disabilities and Autism Team**

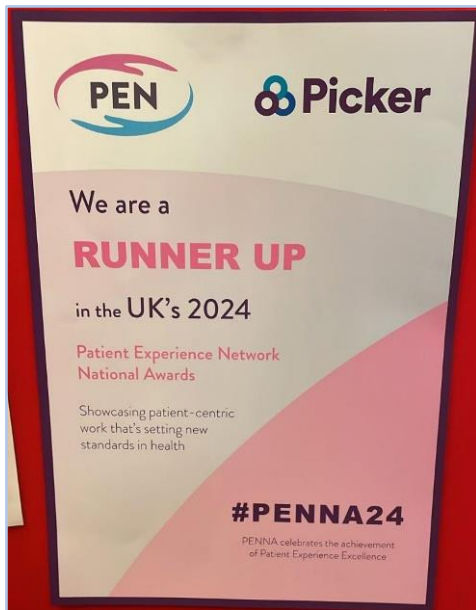
We know how challenging Emergency Departments can be for learning disabled and autistic individuals and the Emergency Department Care Bags clearly have improved the patients' experiences. Keep breaking down the barriers and set examples that more trusts can follow.





### 6.3 Patient Experience Network National Awards (PENNA)

In October 2024, the team was invited to join the PENNA conference after successfully being shortlisted in the category: Innovative Use of Technology, Social and Digital Media. This follows the teams work to incorporate Virtual Reality within healthcare to improve the patient experience and access care, thereby reducing health inequalities for patients with a Learning Disability/ Autism. The team has a keen focus on the use of Virtual Reality to ensure patients get the right care, first time.



### 6.4 Hello my name is...

In July of 2024 Cherie Andrews (Senior Clinical Educator for Learning Disabilities and Autism at LTHT) led the organisation in learning how to utilise Makaton to sign "Hello my name is" as part of the organisations re launch of the initiative. We are proud to have supported this piece of work, breaking down communication barriers and supporting therapeutic relationships between staff and patients.



## 6.5 Positive Lives Review

In 2024 the team was visited by Anne Marie Glasby a Senior Development Office for Changing Our Lives. Changing our Lives was commissioned by NHS England to create a competency framework for Acute Liaison Roles. The LTHT Learning Disability and Autism Team is planned to be heavily featured within the report and framework providing examples of best practice. The framework will be launched with an article entitled “A Whole Team Approach” which is written on our service as a whole. We are excited to be part of the launch of this in 2025.

## 6.6 Links with Paediatric Phlebotomy

The team has worked hard to make paediatric phlebotomy more accessible to patients with a learning disability and or autism. Often the patients we support find this environment difficult to navigate and long wait times were leading to poor outcomes and distressing experiences. As a result of quality improvement and education work Paediatric Phlebotomy offers two clinics a week where there are pre bookable appointments for our patient population, they are then supported the access phlebotomy with the support of a clinician from the Learning disability and autism team. This has had greater patient outcomes and reduced the need for sedation and inpatient bed days to achieve routine monitoring.

## 6.7 Super Saturdays

The team has supported the Paediatric Saturday Blood Test Clinic ([PSBC](#)) since 2023. The aim of the PSBC is to support children and young people that are LTHT patients who may be more anxious or have a fear of blood tests, sometimes due to past negative experiences or phobia. Patients that have Learning Disabilities and/or Autism can access the clinic with our support. The benefits to it being on a Saturday are that it avoids disruption to their usual routines and the department is much quieter as it is not open to walk in referrals from GP's. It is a low stimulation environment and preparation for the intervention is done beforehand to ensure that the person has reasonable adjustments plan in place that is used on the day.

Each patient is allocated a booked appointment of 30/45 minutes.

They can be supported by a Play Therapist and Learning Disabilities Team Clinician with play-based desensitisation/role play, have extra time to settle into the environment, access to distraction equipment such as iPad, Virtual Reality Headset, sensory equipment. There is a Qualified Children's Nurse present to administer [red](#) local analgesic cream or spray if needed.

## 6.8 Baby Suitcases

Diffability, the charity who supports this project was set up by a parent who had a negative experience when being told that their baby boy had a diagnosis of Down

Syndrome. She set out to ensure that no parent had the same experience. She worked with local and national charities ~~they to~~ ~~launched~~ the “Baby Suitcase’s”. The Learning disability and Autism team worked alongside Diffability, Maternity services at LTHT and Local Leeds Charity Sunshine and Smiles to implement the cases. At the start of the launch, we were expecting approximately 10 babies to be born in Leeds with a down syndrome diagnosis annually. However later established this was nearer to 30- 40 babies annually. Through this project we have been able to ensure that babies born at LTHT have a Learning Disability PAS flag, to ensure that in the future they are able to access reasonable adjustments aiding better access to healthcare longer term. Due to the demand for these cases Leeds Hospital Charity has financially supported the initiative to ensure continuation of the baby suitcases within LTHT.

Families report that the cases are a lovely mode of support, providing information in an emotionally intelligent manner, removing stigma and forging relationships and signposting to local clinical teams and charities.



## 6.9 Oliver McGowan Training - Employment of Co Trainers

Two Co Trainers with Lived Experience of Learning Disabilities and Autism have been successfully employed via the Staff Bank at Band 5. This ensures that staff training at LTHT is co-produced and co facilitated. In line with the recommendations from NHSE, the Autism Act (2009). The NHS Long Term Plan - “Statutory guidance states that a key duty is to provide training for all frontline public service staff in line with their job role and developing specialist training for staff in health and social care”; and reflected in LTHT Autism and Learning Disabilities Strategy. LeDeR Programme (2020/2021) highlighted the need for “mandatory learning disability awareness training for all staff supporting people with a learning disability and or Autism”.

The training sessions are evaluated positively, and the main theme of feedback is how impactful the lived experiences are.



## 6.10 Snapshot of some of our other activity to promote awareness and health equity



**Learning Disability and Autism Team**

**The Leeds Teaching Hospitals NHS Trust**

**Have you thought about these for your patient?**

Always search PPM for a Health Passport - ensure it is up to date and clinically relevant

**Think reasonable adjustments:**

- Mental capacity
- Independent Advocacy
- Communication
- Sensory needs
- Carers Passport
- Easy read information
- Enhanced Care
- Understanding of medication
- Adapt the environment

**People with a Learning Disability and/ or Autism are still dying, on average, 20 years earlier than those without. Think about the risks and avoidable causes of early death:**

- Poor oral health
- Sepsis and aspiration pneumonia
- Nutrition and hydration
- Red flags for Cancer and Screening
- Deconditioning in hospital
- Constipation
- Posture and mobility
- Weight management

**Think early referral to specialist support services like:**  
Dietitians, Speech and Language, Physiotherapy, MCA/MHA and Palliative Care teams

**The Learning Disability and Autism Team:**  
 leedsth-tr.lautism@nhs.net 0113 20 66836

**Learning Disability and Autism Team**

**How you can support our patients:**

**NHS The Leeds Teaching Hospitals NHS Trust**

- staff champions**: Think Staff Champions: in your area, they are:
- care bag**: Check if they need any Reasonable Adjustments or sensory support:  
Acute admission – offer Care Bag
- hospital passport**: Have they got a Hospital Passport?  
Please search PPM+ The Hospital Passport ([leedsth.nhs.uk](http://leedsth.nhs.uk))
- talk about carers**: Who is supporting them?  
Offer Carer's Passport  
Non directly paid carers contract  
Enhanced Care

We have lots of Easy Read leaflets for common procedures

Scan here!

Email the LD/A team with their NHS number: [Leedsth-tr.ldautism@nhs.net](mailto:Leedsth-tr.ldautism@nhs.net)

## 6.11 Quality Improvement

Last year saw our quality improvement work grow following permanent funding for the post. During 2024-2025 this work has been embedded into business as usual with projects being finalised and handed back to CSUs for ownership.

### Paediatric Dental

The paediatric dental pathway has been completed and the Leeds Dental Institute now facilitate this clinic in house with no support from the Learning Disability and Autism Team. The clinic ensures children who need reasonable adjustments have been offered them before their first appt to tackle the health inequalities faced with access to healthcare. This process has ensured that for many children and young people their reasonable adjustments are shared throughout the process from outpatient appointments to admission, reducing the strain on parent carers and the workforce.

### Acute Care Bags

The team continues to offer the acute care bags within the emergency departments, CAT Unit and Surgical Assessment Unit. Thirty-two other Trusts now use the care bags and three have secured permanent funding for these, something which we are keen to explore next year as we demonstrate the continued reduction in repeat attendance for this patient group.

### Work with Patient Hub



We are core members of the Trust 'Task and Finish' group for Patient Letters. The aim is to improve accessibility of all the letters sent by the Trust, thus improving patient outcomes. We redesigned the standard letter to reduce word count, improve readability and include an Easy Read summary as standard. We have added 'Easy Read preferred' as a preference for all our patients with a Learning Disability electronic alert on Patient Hub, this is the system that generates 80% of letters. Our next steps are to monitor missed appointment rates, where we will hopefully see a reduction in the health inequalities gap.

## **Patient Flags**

The team continues to promote electronic PAS flags for our patients and has recently reached 10,000 flagged patients. There are now 4,000 Autistic patients with the relevant flag and 6,000 patients with a learning disability recorded on PAS. Any patients with a learning disability moving forward will also receive the relevant "Easy Read Preferred" preference for communication from the Trust.

## **Education**

With support from our Senior Clinical Educator the team continues to target areas of the organisation for "Learning Bursts". An example of this is following an adverse event on a paediatric ward the team worked closely with the ward manager to establish training deficits and deliver a training package to improve understanding, skill, and confidence within the nursing and wider workforce. This is in addition to the Oliver McGowan Mandatory Training which is being delivered with the Co-Trainers.

### **6.12 Training and Education**

The provision of training across the Trust continues to show a clear increase and our aspiration is to increase the number of trained staff year on year. The Clinical Educator for Learning Disabilities and Autism is working with senior colleagues in the

ICB, Corporate Nursing and Organisational Learning team to increase the number of staff who access training and to accurately record completion levels.

-Training has been provided via

- E Learning
- Bespoke learning bursts
- The Excellence in Practice Programme
- Staff Champion sessions
- Band 3 education programme
- Education sessions for students
- Tier 1 Oliver McGowan Training Pilot

The internet and intranet pages for Learning Disability and Autism continue to be a source of information for patients, carers, and staff.

The team has also continued to take part in conferences and training programmes as participants and presenters. This year our Quality Improvement Clinician was invited to take part in the parliamentary round table discussion at the Department of Health. This was following an ombudsman report into DNACPR decisions over the last 5 years. The aim of the round table was to show case excellent practice and inform the government strategies moving forward to implement the recommendations.

The team has worked hard to improve RESPECT quality at LTHT continue to be at the front of implementing recommendations for our patient group.

## **7. Lessons Learned: PALS, Complaints, Audit and Datix**

We continue to collate data from PALS, Complaints, Audit and Datix. Themes are then pulled and shared via the Safeguarding, Learning Disabilities and Autism Governance Group with actions in line with the Learning Disability and Autism Team workplan.

We are proud to report that we can again report that despite another annual increase in referrals the number of PALS and Complaints on average remain in line with the last annual report. Typically, the team supports less than 5 complaints per quarter, quarter 4 saw a rise in this to 10 complaints. The majority of these relate directly to wait times and the team has already begun work to combat this. Often complaints are not directly related to a person's Autism or Learning Disability however the team remains involved to support the process and quality assure responses. This is done in line with the Ask, Listen, Do principles.

We continue to offer appropriate electronic alerts, reasonable adjustments, and Health Passports for patients we support through the complaint's procedure.

DATIX incidents are now being monitored daily by the clinical team allowing a more timely and patient focused response to each incident, the relevant support is instigated by the named key worker for patients. Incidents are also reviewed monthly by the Quality Improvement Clinician for themes and trends which do show an overall downward trend which is positive and representative of the actions we reported last year as part of our lessons learnt from DATIX summary.

Themes remain steady - Pressure damage, medicine management and falls. Key areas - Children's, Urgent care, SIM and AMS.

### **7.1 Audit Summary**

The Learning Disability and Autism Team runs an audit within Q2, this audit is undertaken in line with the Trust Nursing and Midwifery Audit Programme. The audit is in place to evaluate the service provided to and experienced by patients with a

learning disability and or Autistic patients. The audit is a cross-sectional iterative audit meaning it observes information at a set point in time in several places. Since the last audit we have undertaken several pieces of work which have contributed to an increase in positive responses:

1. Region wide promotion of Health Passport including an accessible poster which is being advertised in GP surgeries and health centres.
2. Feedback received regarding the inability to complete the form digitally - this has been reviewed and is now ready for launch.
3. All patients coded with the "LD2" [PASpas](#) flag will now also be coded as "prefers easy read" and accessible information will be sent to them regarding preparation for coming to hospital, this also includes accessible information on the Health Passports.
4. The Learning Disability and Autism Team also supported the relaunch of the "Hello my name is" campaign showing the importance of representation and inclusivity by teaching many staff this phrase in Makaton.

## 7.2 Areas for Improvement/Lessons Learnt

1. A reduction was noted in the last year in the number of staff accessing support directly from the team, the intranet and internet pages. However, referral rates remain consistently high. This could reflect increased confidence in the workforce however no data to support this.
2. There has been a reduction in the number of easy read leaflets given to patients.
3. There has been a reduction in the number of staff champions and awareness of this programme.
4. The local element to the Learning Disability Improvement Standards has been removed from the programme.

## 8. Case Reviews: Learning Disability Mortality Reviews (LeDeR)

27 deaths of people with a Learning Disability or Autistic people were reported to the LeDeR programme, representing a significant decrease from the year before (49 in 2023-2024).

This is at a time where we continue to see an increased number of flagged patients and a stable referral rate. Data is now improved as the QI Clinician is now able to routinely monitor all LTHT monthly mortality records and not just patients active on the LD and A caseload or those directly referred in on death.

Most deaths followed national themes. The most frequent causes of death were pneumonia (including aspiration pneumonia) and sepsis. These themes are monitored via the city-wide work plan meeting and the LeDeR meeting.

Regionally we support the LeDeR program and as of March 2025 Leeds has 18 reviews outstanding - 2 moving to Focussed - 1 on hold awaiting coroner - 3 ongoing 12 awaiting allocation.

The QI practitioner shares all relevant information and meets with reviewers as needed. We are core members on the regional panels and share best practice and learning as needed.

The ICB LeDeR structure is currently changing with the Lead leaving post this month.

Advanced Care Planning and ReSPECT has been a focus of the LD and A team this year. The aim being to reduce the inequality gap around access to advance care planning conversations. This work has been supported by our local audit and the national parliamentary paper;

[End of life care: improving DNACPR conversations for everyone | Parliamentary and Health Service Ombudsman \(PHSO\)](#)

The QI Clinician and patient partners have worked regionally with the Leeds Palliative Care Network to create a library of resources in easy read format to support all aspects of the palliative patient's journey including Advance Care Planning and ReSPECT. LTHT have reviewed and renewed the policy and this now states that everyone should be offered written information to support advance care planning/ future care planning conversations. These resources are hosted on the LTHT website and the LPCN web pages and will be promoted regionally. We were invited to present this work at the government round table discussions following the publication of the paper. This work has now been circulated as an example of excellent practice.

One case taken to LeDeR panel this year raised concerns regarding care in LTHT and we have been fully involved in this review. Issues raised were - communication around PEG feed care and competence and availability of PEG feed equipment. As a result of this case, we have re-written and published our Easy Read materials around PEG care and equipment in the hospital, advising patient's and those who support them to always have a spare set of equipment and to bring this with them when they attend the hospital acutely.

## **9. Serious Incidents**

Any potential patient safety incidents are escalated via risk management, and investigated by the appropriate service. Learning is captured by the relevant group or committee.

### **Looking Forward: 2025-2026:**

#### **9.1 The Learning Disability and Autism Team Strategy for 2025-2028.**

This year we have reviewed the LTHT strategy for Learning Disabilities and Autism, this included a consultation phase with key stakeholders both internally and externally. The strategy outlines our commitments as a team to the organisation and our patient population for the next three years. Additionally, to this the strategy outlines the expectations of other CSUs regarding LD/A and how we can continue to strategically push forward with improved patient care. The strategy is due to be launched May 2025.

## **9.2. Learning Disabilities and Autism Policy for Leeds Teaching Hospitals.**

Currently there is no Trust wide policy for LD/A within LTHT. Guidance comes direct from the team on a case-by-case basis. During 2025 we plan to change this with the introduction of a policy, providing clinical guidance and setting standards across the organisation. This will also outline the Trusts statutory obligations to reasonable adjustments and ensure that these are implemented and upheld out of our service hours.

## **9.3 Diamond Pathway Launch**

In 2025 the team will launch the “Diamond Pathway”. The pathway is designed to be utilised across the organisation and outlines key considerations for CSU’s when supporting a patient with LD/A in line with the equality act and the policy which we aim to be launched at the same time. The pathway is being implemented to support and empower front line staff to provide reasonable adjustments without the need to always refer the team. The aim of this is to always ensure continuity of care across the organisation, reducing dependency on the LD/A team being available to offer support.

## **9.4 Implementation of The Oliver McGowan Mandatory Training**

May 2025 will see the pilot of Tier 1 of The Oliver McGowan Mandatory Training with Estates and Facilities, The New to Care Programme for Band 2, The introduction to professional practice programme for band 4 & 5 associate and registered nurses. We continue to await the finalised code of practice for this training however in the absence of this we will differentiate which staff will complete Tier 1 & 2 through a training needs analysis to ensure this important training is rolled out across LTHT.

## **9.5 Learning Disabilities and Autism Audit**

The Learning Disability and Autism Team will be working with colleagues in Quality to review the quarter 2 audit. The new audit will incorporate the Trust goals for Learning Disability and Autism as outlined in the strategy. Additionally, this will be written with key considerations for the statutory obligations for Learning Disability and Autism and the relevant NICE Guidance. The new audit will offer greater assurance and link directly to our plans for Learning Disability and Autism providing us meaningful data

on the goals we outline in the strategy. We want to push the Learning Disability and Autism Agenda in line with the Trust plans for ward metrics.

## **10. Conclusion**

During the 2024-2025 reporting period we have made significant strides in improving access, equity, and outcomes for individuals with learning disabilities and autistic people. Through a combination of targeted education, inclusive policy development, patient-centred quality improvement projects, and strong partnership working, we have continued to embed a culture of dignity, respect, and tailored care across the Trust.

Our achievements - from national award recognition to innovative projects like the Care Bag Scheme and Paediatric Phlebotomy Clinics - demonstrate our commitment to breaking down barriers in healthcare. We have strengthened our workforce through the inclusion of Co-Trainers with lived experience and maintained momentum in the rollout of essential training, including the Oliver McGowan programme.

As we look ahead to 2025-2026, we remain focused on delivering our new three-year strategy, formalising Trust-wide policies, and embedding sustainable systems that empower all staff to provide appropriate care and support. With a shared vision, dedicated resources, and a focus on continuous improvement, we are confident in our ability to lead change and champion the voices of people with learning disabilities and autism throughout the organisation.

We extend our deepest thanks to our patients, carers, staff, and partners for their ongoing engagement and commitment. Together, we continue to shape a more inclusive, responsive, and equitable health service.