

# **Learning Disability and Autism Team Annual Report 2022- 2023**



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## Foreword

Leeds Teaching Hospitals NHS Trust is committed to ensuring all our patients with Learning Disabilities and/or Autism receive equitable access to healthcare.

As we move into 2023-24, the Leeds Teaching Hospitals NHS Trust (LTHT) Learning Disability and Autism Team is pleased to share their second Annual Report.

The evidence presented in this report provides information and assurance as to how we as a Trust meet the standards set out in national guidance for patients with Learning Disabilities and/or Autism.

The Learning Disability and Autism Team wishes to thank all our dedicated staff, our patients, our supportive partners, the Executive Team and the Trust Board who continue to work so positively with us to reduce health inequality and improve care for patients with Learning Disabilities and/ or Autism.

**Our Aim:** To provide outstanding care for people with Learning Disabilities and/ or Autism, throughout their lives. We aim to offer the right care at the right time and are supporting patients to receive what they need at the first attempt.

To achieve this aim, we work in partnership our patients, their families and support networks to enable us to deliver a positive patient experience.

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# 1 Introduction

We are pleased to share the second Leeds Teaching Hospitals NHS Trust (LTHT) Learning Disability (LD) and Autism Annual Report. LTHT, the Executive team, the Learning Disability and Autism Team and managers are committed to reducing health inequality and improving the care we offer to people with LD and/ or Autism and their families, in the Leeds Way.

The 2022-23 annual report provides the Trust Board with:

- An overview of the national and local context for the LD and Autism agenda
- Information about accountability and assurance
- An overview of the specialist provision for LD and Autism at LTHT.
- Key achievements in 2022-23
- Learning and challenges in 2023-23 and the plan for ongoing improvements in 2023-2024.

All patients should be able to access health care in a way which meets their individual needs. The Learning Disability and Autism Team continues to support our wider workforce, patients, their carers and other professionals supporting them, to ensure that they can access care in a way which is equitable. The team continues to offer an innovative multi-disciplinary structure and, in line with our strategy (<https://www.leedsth.nhs.uk/assets/Publications/5c28216b6d/LTH4119.pdf>), works across multiple levels:

1. Direct specialist intervention
2. Indirect specialist support / liaison
3. LTHT - wide work - raising awareness, training the workforce, adjusting pathways
4. Wider engagement from the individual patient, to the service and the wider picture of seamless health provision in the city.

The LD and Autism Team offers support to patients across the lifespan, therefore this report offers assurances about the care of children and adults.

## 1.1 Definitions

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

These two terms are currently used interchangeably. LD/ ID include the presence of:

- A significantly reduced ability to understand new or complex information in learning new skills, with:
- *A reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development'* (Valuing People, 2001)

LD might also be called (amongst other terms) global developmental delay, special needs, SEND, additional needs, impaired intelligence.

**Autism:** Autism is a lifelong developmental disability which affects how people communicate and interact with the world. (<https://www.autism.org.uk/advice-and-guidance/what-is-autism>). Autism is often referred to as a 'spectrum' as no two Autistic people are the same, they each have different profiles and preferences. Autism might also be called: Autistic Spectrum Condition (ASC), Autistic Spectrum Disorder (ASD), Asperger's

**Neurodiversity:** an umbrella term which covers many presentations, many of which are currently outside the scope of the Learning Disability and Autism Team.

## **2 Learning Disability and Autism: Current Drivers**

There are a number of national, regional and local documents offering guidance about the care of people with Learning Disabilities and Autism. Many of these were described in the last annual report and are now well established. As a Trust we have dedicated workstreams in place to meet National Standards and demonstrate compliance.

### **2.1 National:**

- 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

### **2.2 Local/ Regional:**

- Leeds Autism Strategy
- Leeds 'Being Me' Strategy
- Feedback from Leeds LeDeR panel
- West Yorkshire and Harrogate Health and Care Partnership, Mental Health, Learning Disability and Autism Strategy:

### Within LTHT:

The team also seeks to respond to local feedback:

- Feedback from patients and stakeholders e.g. PALS, complaints, compliments
- Feedback from LTHT staff
- Audits led by the LD and Autism Team e.g. care audit, ReSPECT audit, internal mortality review

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

The Learning Disability and Autism Team has undergone significant change over the last five years, in response to a growing understanding of the needs of our patient group within LTHT and beyond. The Learning Disability and Autism team at Leeds Teaching Hospitals Trust seeks to respond flexibly to the needs of our patients and the people who support them.

The health/care challenges faced by people with Learning Disabilities and Autism are well known and we continue to see similar themes reflected in national literature over many years. For example, premature (potentially preventable) deaths, diagnostic overshadowing, respiratory care, communication and constipation. Furthermore, it is acknowledged that health inequality widened during the COVID-19 pandemic, with increased adverse outcomes experienced by people with Learning Disabilities and Autistic people. We continue to see long lasting effects of this, although symptoms of long covid are often underreported. These include the direct physical effects of Covid-19 alongside indirect consequences such as mental ill health, weight gain and associated mobility/ respiratory issues and a general mistrust of health services following controversy around the use of the clinical frailty scale and inappropriate use of Did Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) recommendations in some providers of which LTHT has never been one.

### **4 Governance Arrangements for LD and Autism**

#### **4.1 Roles and responsibilities:**

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.

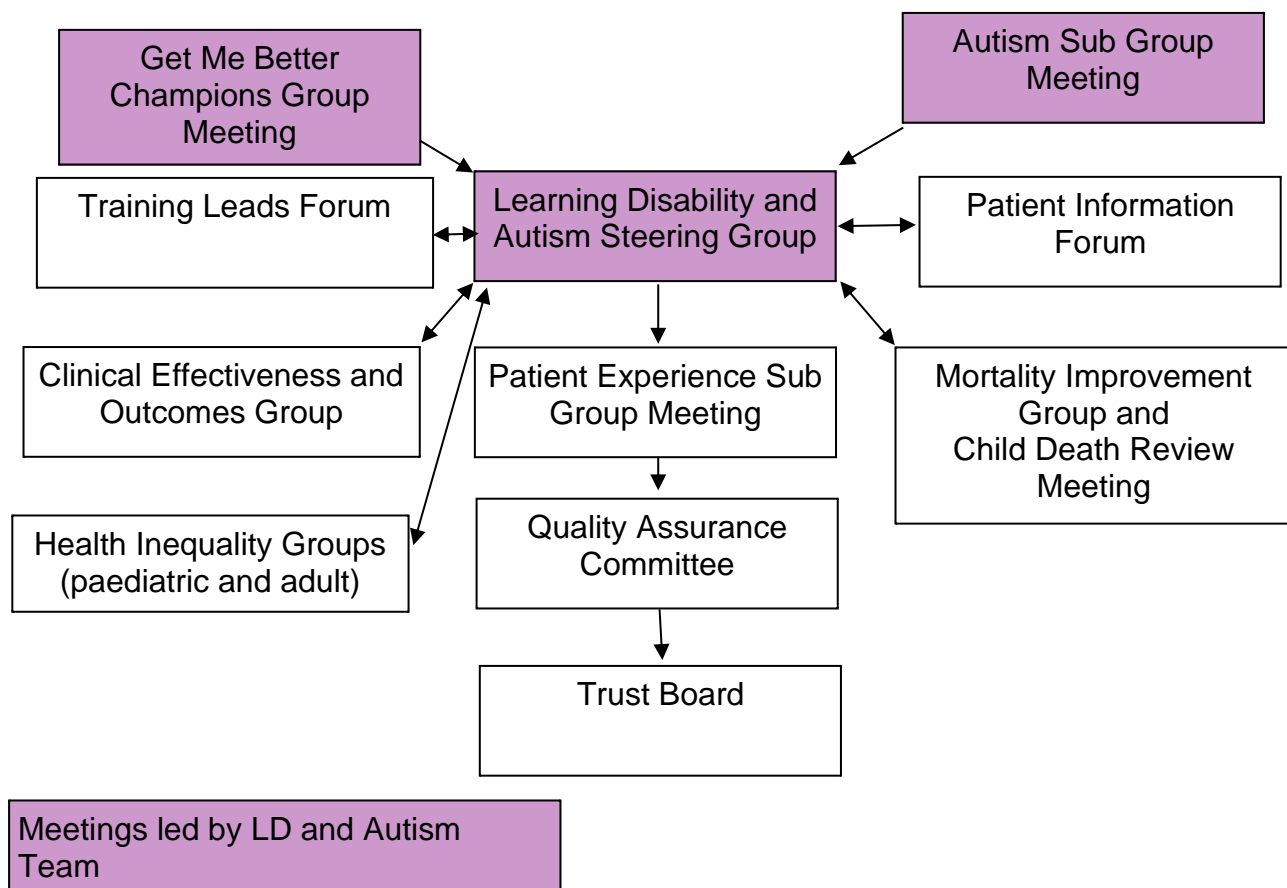
The Lead Professional for LD and Autism provides the organisation with operational advice, support and input. The LD and Autism Team professionals are committed to supporting the workforce in understanding the needs of patients with LD and Autism.

Governance groups provide challenge and assurance with regard to 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 in service.

#### **4.2 LTHT LD and Autism Governance Structure.**

The LD and Autism Team offers assurance in the following structure at LTHT:

Figure 1: Floor to Board Governance for LD and Autism



The Learning Disability and Autism Team also attend the following meetings within LTHT

- Carers Forum
- Dementia Steering group
- Patient Equality and Diversity
- Accessible Information Standards Meeting
- MCA/ MHA steering group
- DeEscalate Collaborative (two of the team are faculty members)
- Safeguarding Governance group
- Chief Nurse CSU meetings

#### 4.3 External (Local and Regional) Assurance:

Locally and regionally, assurance updates are given to the following meetings:

- Learning Disability Partnership Board
- People's Parliament
- Health Task Group

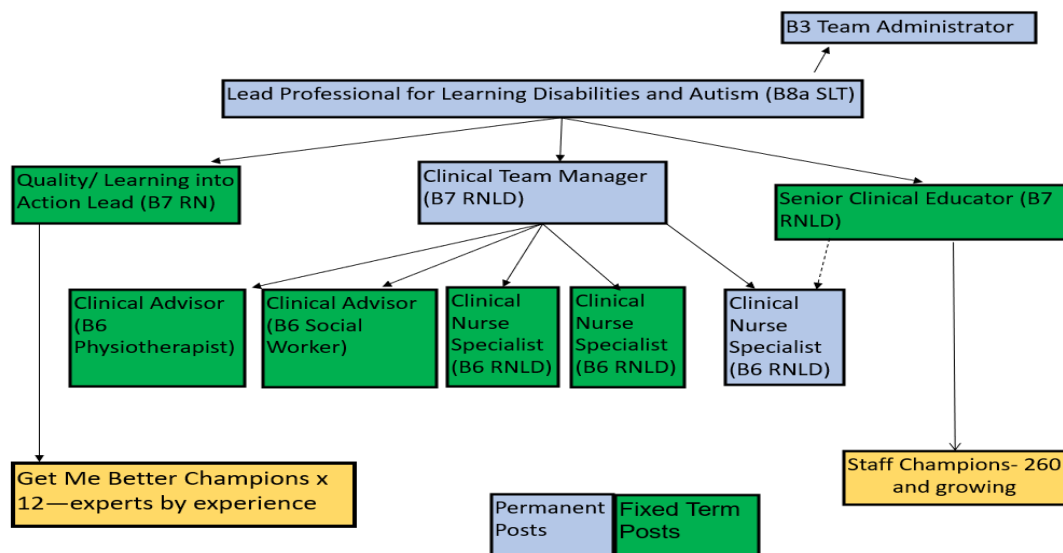
- Autism Partnership Board
- SEND Partnership Board
- SEND Health Task Group
- Leeds LeDeR Panel
- Leeds LD and Autism Work Plan Meeting
- Yorkshire and the Humber Access to Acute Network (LD and Autism Lead is the vice chair)
- WY and H Learning Disability and Autism Monthly Steering group/ Challenge Group
- WY and H Oliver McGowan Steering Group and working group
- Healthwatch meetings in Leeds, related to Learning Disability and Autism

#### National

- Contribution to national forums ad hoc.

## 5. Current structure and core business of the LD and Autism Team:

Figure 2: Current structure: permanent posts in blue and temporary posts in green



The current establishment has been in place since Autumn 2021 and now supports three established branches of work- clinical, training of the workforce and quality improvement.



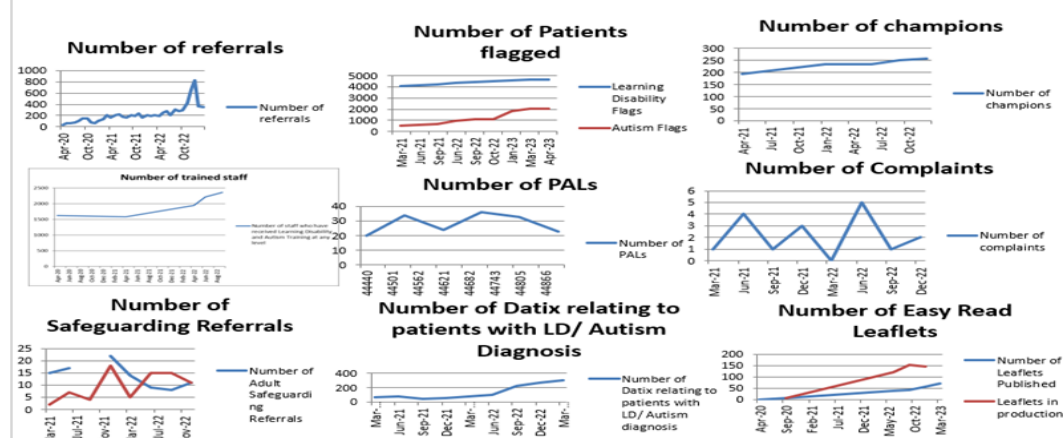
The team also:

- 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
- Is developing 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 11 Get Me Better Champions employed 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/ ICS agendas for Learning Disabilities and Autism
- Acts as a regional lead for Acute Liaison, offering support to other Acute Liaison clinicians via the Access to Acute Network as required.
- Offers an MDT approach, with physiotherapy and speech and language therapy directly targeting known areas of need, 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.
- Although the LD and Autism Team is a service for patients, due to a growing number of queries, the team has taken a lead role in supporting the development of a staff support webpage, for staff who are neurodivergent and their line managers.

Further information and associated evidence about the work of the team is captured in the LD and Autism team work plan. This live document shows the work that the team is undertaking and is mapped against the Learning Disability Improvement Standards.

The activity of the team can be seen in the dashboard below:

*Figure 3: Learning Disability and Autism Team Dashboard*



## **6 Key LD and Autism Team Celebrations and Achievements in 2022-2023**

### **6.1 Celebration events**

The team recognises Autism Acceptance, Autistic Pride and Learning Disability Weeks. The team was pleased to see a return to engagement in person for some of these events. Celebrations were also shared via LTHT communications and on the LD and Autism twitter account (@getmebetter).

Autism Acceptance was marked with the launch of a new Autism Health Passport, which had been co-produced by the Autism Subgroup and partners across the city. This new passport has received extremely positive feedback from patients and LTHT staff.

LD week was recognised with public events for the first time since 2020. The LD and Autism Team, along with the Building the Leeds Way Team, shared a stall at two main events: the Council Takeover and the Aspire Learning Disability Picnic in the Park. Information was shared about the work of the team and an accessible consultation was offered about what people with Learning Disabilities would like to see in any new hospital buildings. This feedback was shared with the planners.

### **6.2 Key achievements of the LD and Autism Team**

The work of the team was recognised by two national award programmes:

1. Shortlisted for the Nursing Times 'Workforce Team of the Year'
2. Shortlisted for the National LD Awards in the 'Breaking Down Barriers' category

The team has also been asked to share their work as an exemplar in multiple national forums.

In turn, the team also aim to empower others by celebrating the achievements of the wider workforce. This is currently done by using social media (twitter) with a #ThankYouThursday for a team or individual in the Trust each week.

The key achievements for the year are divided into the three workstreams: clinical, quality improvement and education.

#### **6.3.1 Clinical: Inpatients**

The team is pleased to remain in a position which allows for all inpatients, who are flagged to show their Learning Disability or Autism Diagnosis, to be seen within two working days of admission. Patients typically receive the following support

- Initial Assessment and identification of Reasonable Adjustments
- Ongoing review, including LD/ Autism specialist support to access required treatment (face to face or remote, depending on patient need). Examples of specialist support would be desensitisation, intensive interaction or use of our new Virtual Reality equipment to enable access to care.
- Open offer for treating teams to contact the LD and Autism Team for specialist support
- Support to promote safe and successful discharge

The exception to this is patients who are admitted for a short period only and discharged outside of the working hours of the team. Further work is required to understand the needs of this patient group.

### **6.3.2 Clinical: Outpatients/ Planned admissions**

Outpatients/ Patients identified for planned admissions are offered planning to promote successful attendance, where this is an identified need. Planning may involve phone calls to discuss reasonable adjustments, sharing of information between patients/ existing support network and LTHT clinicians, desensitization or other preparatory work. Where possible, the team supports liaison for combined procedures to reduce theatre attendance and repeated general anaesthetic. The LD and Autism Team may attend the outpatient appointment if this is felt to be a priority. For example, in complex patient care where specialist liaison skills are needed to support the patient to engage in the appointment, or where complex care coordination is required. The team does not have scope to attend all outpatient appointments, but often this is not necessary if the right adjustments are already in place.

### **6.3.3 Quality Improvement**

The addition of a Quality Improvement Clinician to the LD and Autism Team has allowed for accelerated strategic progress within the Trust. This post holder is able to review all feedback streams in a timely way, identify themes and implement pathways or service improvements. The team continues to support projects in a number of key areas, with colleagues at a Band 6 level also now leading individual projects to reflect their own specialist skills and interests.

Recent examples of improvements are as follows:

Emergency Department Care Bags- Implemented following feedback from patients about their experience in the Emergency Department. This successful project, whereby each patient with LD/ Autism receives a bag containing information, sensory supports and items for occupation, has been well received by our patients and staff. Thirteen other Trusts are now replicating this initiative already and more are hoping to do so soon. NHS England have created a film about the care bags as an example of excellent practice.

How A&E can be more accessible for people with a learning disability and autistic people - YouTube

NHS Benchmarking and the LeDeR team have also asked to feature this work in good practice guidance.

Funding has been secured for a second set of bags, so that the Emergency Departments can continue to provide the bags and the project can be upscaled to all admitting areas.

Endoscopy Pathway- This pathway, which aims to ensure that patients requiring endoscopy achieve this at the first attempt, is almost complete. The majority of patients are now achieving endoscopy without the complications which were previously noted by patients, their carers and the ward teams.

Accessible Leaflets/ Letters- In partnership with the Patient Experience team, medical illustration team and leaflet authors, there are now over 75 accessible leaflets live, plus several patient letters. All of these have been co produced by people with Learning Disabilities/ Autism. Carers have also contributed to these

leaflets, which support the work of the Trust towards the Accessible Information Standard. Additional temporary funding has been secured for these, with onward funding for production of the leaflets being considered by the Patient Information Forum.

Surgical prioritisation- A matrix to support patient prioritization has now been agreed and is now in the final stages of e-form development. This matrix will support clinicians to better understand the individual risks whilst patients with LD and Autistic patients await surgery. The risks can then inform re- prioritization if needed.

Information Sharing/ Data Quality- This has been a focus for the team since the last PESG report. The DATIX reporting has improved for our patient group. Early notification of diagnoses from CAMHS support early flagging of patients and hopefully this will support more positive experiences from younger in life. Reporting systems are now in place so that waiting lists can be analysed in greater detail for our patient group.

### **6.3.4 Training and Education**

The provision of training across the Trust remains an area in which development steps are in place. The Clinical Educator for Learning Disabilities and Autism is working with senior colleagues in Corporate Nursing and Organisational Learning team to increase the number of staff who access training and to accurately record completion levels.

Training is now provided via-

- E Learning
- Bespoke learning bursts
- The Excellence in Practice Programme
- The Internationally Recruited Nurses Induction Programme
- Staff Champion sessions

The Oliver McGowan Mandatory Training for Health and Care Staff is partially live and discussion about a potential roll out is underway, locally and regionally.

Although the final Code of Practice is not yet available, preliminary plans are in place for the delivery of level one- a session with both an elearning and a taught component. LTHT have the first 'trio' (Clinical educator, person with a Learning Disability and Autistic person) who will train other trios across the region.

Two of the trio have also received training to deliver level two of the Oliver McGowan training.

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

Data continues to be received from PALS, Complaints, Audit and Datix. Themes are shared to the Learning Disability and Autism Steering Group and related actions are added to the work plan of the team.

## 7.1 PALS and Complaints

The Learning Disability and Autism Team now review all PALS and Complaints, where it is identified that these relate to people with Learning Disabilities and Autism. Thankfully despite an increase in patients, the numbers of PALS and complaints have not increased, with fewer than 5 complaints per quarter and 10 PALS per month (which can be either compliments, updated forms or concerns). Concerns are not frequently related to Learning Disability or Autism but where this is part of the concern, the team will support the response and identified actions. If the concern relates to a patient needing a Health Passport or specialist support, these are offered. Often concerns were related to wider themes within the Trust, for example, waiting times.

## 7.2 Audit Summary

The Learning Disability and Autism Trust Wide Audit was carried out in quarter 2 of 2022-2023, with the following outcomes.

### Positive areas

- 100% of patients asked thought that staff were friendly.
- 97% of patients felt listened to
- 79% Patients had an appropriate Flag in place > 10% increase since last year
- In total 60% of patients had a Passport and all of these were available electronically (8% increase since the previous audit)
- 94% of patients had written evidence of their needs
- 64% staff contacted the LD/A team for advice and support - this is a year on year increase from 20% to 40% to today's figures.
- 70% of staff accessed the intranet pages for support which is a huge increase.
- 79% of staff said they had completed some LD/A specific training
- Staff Champions rate has increased to higher than pre pandemic levels and is now at 79% of areas having a named LD/A champion

### Considerations

To consider	Plan
There was a reduction in number of patients who knew their plan for going home	<ul style="list-style-type: none"><li>• QI Clinician now attends the Trusts discharge collaborative</li><li>• QI clinician working with Palliative Care Team, Discharge collaborative and LDSW team to create a joint Discharge Pathway and increase accessible information available regards discharge process</li></ul>
Only 13% of patients were confident they had been given an accessible Friends and Family Test (FFT)	QI Clinician has discussed with the FFT team and Comms and is organising a screensaver to promote the FFT Easy Read across the Trust and QR code to be added to all new or reviewed Easy Read leaflets to FFT

There was a slight reduction in staff understanding the term reasonable adjustments (100% down to 97%)	<ul style="list-style-type: none"> <li>LD/A team now have training available to all staff at LTHT</li> </ul>
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Data can now be compared over a three year period, illustrating improvements over time. Data is also presented annually to NHS Benchmarking, however, the results are not available for 2022-2023.

### 7.3 Datix report summary:

Datix reporting has increased since the template was updated. There is now a blank field for the question: 'does this incident involve a person with a Learning Disability/ Autism diagnosis'. The following themes and actions have been identified.

Cause	Action
Aggression/ Assault	<ul style="list-style-type: none"> <li>(not that figures are skewed by high volume of incidents from a small number of patients)</li> <li>All appropriate staff in LD/A completed PMVA training, wider work with the DeEscalate collaborative to support patients displaying behaviours of distress.</li> </ul>
Falls	<ul style="list-style-type: none"> <li>Decrease seen in November and December</li> <li>Falls prevention and Falls assessments Easy Read published in November and now given to all patients following a fall</li> <li>To roll out comms regards easy read leaflet via falls prevention team so all patients identified as risk of falls receives a leaflet</li> </ul>
Medication	To continue to monitor monthly and if increase new trend QI Clinician to work with pharmacy to complete RCA
Tissue Viability	QI Clinician working with TV and Dietician team on accessible information regards weight management, monitoring and assessments and prevention in hospital Ongoing reporting to the LD and Autism steering group.

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

31 deaths were reported to the LeDeR programme, representing a slight increase from the year before.

The majority of deaths followed national themes. The most frequent causes of death were: pneumonia (including aspiration pneumonia) and sepsis. No themes were identified during mortality reviews. Cases taken to the LeDeR panel did not raise any major concerns for LTHT in terms of patient care. Typically the patients had been known to the LD and Autism Team, with support provided where needed. Usually, any learning has been addressed ahead of the LeDeR review. It was noted that Structured Judgement Reviews varied in depth and timeliness of completion- the QI lead is working with the mortality improvement group to address this.

## 9 Serious Incidents

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

## 10 Looking Forward 2023-24

The team continues to support the local, regional and national agenda to support patients with Learning Disabilities and Autistic patients who are Autistic. With funding secured for the team until March 2024, the Learning Disability and Autism team is proud and excited to be continuing work towards the strategic ambitions of the Trust. These are summarised in the LD and Autism Strategy as follows:

**Patient-centred:** We will ensure that our service is responsive to the needs of the patient, at all steps of their patient journey.

**Fair:** We will seek to embed reasonable adjustments into the standard working pathways of identified departments.

**Collaborative:** We will share our practice, working with partners in Leeds, West Yorkshire and Harrogate and nationally. We will develop our work with teams in key areas, such as sepsis, behaviour support and tissue viability.

**Accountable:** We will monitor performance via feedback about services offered by Leeds Teaching Hospital to patients with learning Disabilities and Autism, responding and offering support as required.

**Empowered:** We will ensure that all staff in Leeds Teaching Hospitals have access to training about Learning Disabilities and Autism, where this is appropriate to their role. We will seek to ensure that patients feel empowered to give feedback.

In line with the Learning Disability and Autism Work Plan the key ambitions of the team include:

- The launch of the new, coproduced health passports for people with Learning Disabilities
- The upscale of the Emergency Departments Care Bags project to all emergency areas
- The pilot of a respiratory screen for people with Learning Disabilities
- The implementation of pathways in key areas, for example, the role out of the PerCEPT (person centred planning tool for elective surgery)
- The upscale of Learning Disability and Autism Training in the Trust, and the training of trios for Oliver McGowan Level 1.
- To secure permanent funding for the LD and Autism Team at LTHT
- To reduce readmissions within 28 days of discharge

## 11 Conclusion

We are pleased to provide this second annual report to demonstrate the activity, processes and ambitions in place in Leeds Teaching Hospitals Trust to ensure our patients with LD and Autism receive high quality care that meets their individual needs.

The LD and Autism Team are proud to lead this work in collaboration with our patient partners, colleagues in the Trust and across the city.

We are more aware than we have ever been of the challenges that people with learning disabilities and Autistic people face when accessing healthcare. However, we are confident that we are building towards a system where all our patients receive the care they need.

With this support in place we hope to continue to receive feedback, demonstrating our impact to the patient experience:

*‘for the first time, I could, instead of couldn’t’*

(Patient attending the Emergency Department in 2022)