

# Our plan for people with learning disabilities and/or autism, their families and carers.

2022-2025



# 1. Foreword



## **Professor Cheryl Lenney OBE** Group Chief Nurse Manchester University NHS Foundation Trust

This strategy demonstrates Manchester University NHS Foundation Trust's (MFT) on-going commitment to improving the health and care of people with learning disabilities and/or autism accessing our services.

Delivering equitable services does not always mean delivering care and treatment in the same way to everyone. People with learning disabilities and/or autism require reasonable adjustments and additional support whilst in our care and we therefore need to involve them in planning services and learn from their experiences.

Our aim is to deliver high quality, safe, person-centred care which provides people with learning disabilities and/or autism and their families and carers with the most positive experience of MFT's services.

I would like to thank everyone who was involved in developing this strategy and for everyone's help and support in realising our aim.

## 2. Background

**There are approximately 1.5 million people with a learning disability living in the United Kingdom with over 1.2 million in England - 951,000 adults and 299,000 children (Mencap 2019 - i). There are an estimated 700,000 adults and children in the United Kingdom with autism, approximately 1% of the population (ii).**

According to the NHS Long Term Plan (iii) people with a learning disability face significant health inequality compared to the rest of the population and on average, die 16 years earlier than the general population – 13 years for men, 20 years for women. The life expectancy gap for people with autism is known to be approximately 16 years compared to the general population (ii).

It is estimated that 20-30% of people with a learning disability also have autism (iv). Despite suffering greater ill-health, people with a learning disability and/or autism often experience poorer access to healthcare (iii).

In 2020, the Learning Disabilities Mortality Review Programme (LeDeR - v) found that people with learning disabilities continue to die prematurely – and although there are some early signs of improvements, there are still considerable differences compared to the general population with 63% of people with learning disabilities dying before reaching the age of 65, compared to 15% in the general population.

**Early and sustained action is required to address the inequalities faced by people with learning disabilities and/or autism.**

# 3. Introduction

**The purpose of the strategy is to set out:**

- **Manchester University NHS Foundation Trust's (MFT) three-year strategy for improving care and experience for people living with a learning disability and/or autism who access the Trust's services.**
- **The Trust's commitment in line with NHS Improvement's (NHSI) National Standards (vi) and identifies the strategic priorities, actions and desired outcomes over the next three years.**

## **Definition of a learning disability and autism**

A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life (vii).

People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people. According to Mencap (2018 - vii) with the correct support most people with a learning disability can lead independent lives. The collective term of learning disability overshadows the person which may lead to their health needs both physical and mental not being identified and met fully.

Autism is a lifelong developmental disability that affects how people perceive, communicate, and interact with others, although it is important to recognise that there are differing opinions on this and not all autistic people see themselves as disabled (viii). People with autism see, hear and feel the world differently to other people. Autism varies widely and is often referred to as a spectrum condition, because of the range of ways it can impact on people and the different level of support they need across their lives.

## National and regional context

There have been several key documents and policies published nationally related to transforming care for people with a learning disability and/or autism. Building the Right Support (2015 - ix) set out a plan to improve health and care services so that more people can live in the community, with the right support, and close to home.

The Autism Act 2009<sup>10</sup> led to the development of the Fulfilling and Rewarding Lives - The 2010 Autism Strategy (xi) which identified the need to improve care and access to services to support all persons living with autism. An updated strategy, The National Strategy for Autistic Children, Young People and Adults: 2021 to 2026 was published in 2021<sup>2</sup>.

In June 2018, NHSI published its Improvement Standards for NHS Trusts (vi). The NHSI National Standards have been developed with a number of outcomes created by people with learning disabilities and their families. These clearly state what is expected from the NHS. By taking this approach to quality improvement, it places patient/service user and carer experience as the primary objective, as well as recognising the importance of how the NHS listens, learns and responds in order to improve care.

The NHSI standards also reflect the strategic objectives described in national policies and programmes, in particular those arising from Transforming Care for People with Learning Disabilities Next Steps (2016 - xii) and Learning Disabilities Mortality Review (LeDeR) Programme (2015 - xiii).

The Greater Manchester (GM) Learning Disability Strategy 2018<sup>14</sup> is based upon collaboration, learning and developing a GM shared approach to service provision and commissioning where this makes sense. The aim of the strategy is to enable people with a learning disability in GM to enjoy independence, live as close to home as possible in communities where they feel valued, to enjoy and have purpose to how they spend their time and to contribute to the local neighbourhood.

# 4. Our strategy

**The Trust's vision as outlined in this strategy is to:**

- **Improve the care and experience of people with a learning disability and/or autism who access the Trust's services**
- **Crucial to this is the Trust's commitment to providing education and training to all staff to support the knowledge and skills required.**

To ensure care is safe, effective, responsive, caring and well-led, engagement with individuals with learning disabilities and/or autism, their families and carers has and will continue to take place.

## **MFT Vision and Values and Strategic Aims**

MFT's vision is to improve the health and quality of life of our diverse population by building an organisation that:

- Excels in quality, safety, patient/service user experience, research, innovation and teaching
- Attracts, develops and retains great people
- Is recognised internationally as a leading healthcare provider.

The strategy for people with learning disabilities and/or autism, their families and carers aligns with the following Trust Strategic Aims:

- To improve patient/service user safety, clinical quality and outcomes
- To improve the experience of patients/service users, parents, carers and their families
- To develop our workforce enabling each member of staff to reach their full potential.

This strategy describes the framework by which the Trust will work towards the vision, values and strategic aims. The framework is guided by the NHSI National Standards<sup>6</sup> for the provision of care for patients/service users with learning disabilities and/or autism<sup>2</sup>.

This strategy sets out strategic priorities for continuously improving the care and experience for people with learning disabilities and/or autism when they access services and were agreed in partnership with individuals with learning disabilities and/or autism, representatives from the Hospitals/MCS/LCOs, representatives of the Local Delivery Groups and MFT LD Steering Group.

**The four strategic priorities are:**

1. Respecting and protecting rights
2. Inclusion and engagement
3. Workforce
4. Learning disability services standard

These standards incorporate the requirements of the National Strategy for Autistic Children, Young People and Adults: 2021 to 2026 (ii), such as access to services, reasonable adjustments and training.

The Trust's commitment to each standard is shown on the following pages.



# Standard 1 - Respecting and Protecting Rights

**We will ensure we meet our Equality Act Duties to patients/service users with learning disabilities and/or autism and that the wider human rights of our patients/service users are respected and protected, as required by the Human Rights Act.**

## **We will ensure:**

- Patients/service users can access highly personalised care and achieve equality of outcomes.
- Mechanisms are in place to identify and flag patients/service users with learning disabilities and/or autism from the point of admission through to discharge so reasonable adjustments can be made. Where appropriate, information will be shared as people move through departments/wards/units and between services.
- Processes are in place to investigate the death of a person with learning disabilities and/or autism while using our services and learn lessons from the findings of these investigations.
- Any restrictions or deprivations of liberty associated with the delivery of care and treatment to people with learning disabilities and/or autism, are vigilantly monitored.
- Measures to promote anti-discriminatory practice in relation to people with learning disabilities and/or autism are in place.

## **We will achieve this by:**

- Ensuring reasonable adjustments are clearly documented in individualised care plans and staff utilise reasonable adjustment care plans.
- Staff utilising hospital passports to understand the needs of the patient/service user.
- Developing ward/unit/service information packs and checklists to ensure support for patients/service users is in place.
- Implementation of Matron Reviews across Hospital/Managed Clinical Services inpatient areas to provide senior oversight of the provision of care.
- Information and easy read material being accessible for patients/service users with a learning disability and/or autism.



- Ensuring the Trust identification and flagging mechanism for people with learning disabilities and/or autism is consistent across all hospitals/MCS/LCO with the implementation of HIVE.
- Engagement with the national Learning Disability Mortality Review (LeDeR) programme.
- Ensuring the LeDeR tracker in place also reflects patients/service users with autism in line with the national strategy.
- Sharing lessons learnt from the outcome of investigations of the death of a person with a learning disability and/or autism and from the LeDeR programme via corporate and Hospital/MCS/LCO meetings.
- Utilising the knowledge and expertise of the specialist learning disability safeguarding team into mortality reviews to inform training needs and enabling lessons learnt are shared across the Trust.
- Providing further training of the Mental Capacity Act (MCA) process, appropriate use of Independent Mental Capacity Advocates (IMCA) and completion of Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) forms.
- Ensuring patients/service users, parents, carers and their families are involved in all discussions where appropriate.
- Continue to work collaboratively with community learning disability teams bridging gaps to support patients/service users with a learning disability and/or autism.
- Raise awareness of legislation, Trust policies and Trust values and behaviours, throughout the workforce.
- Continuing to work with the MFT Learning Disability and Autism Patient and Carer Forum.
- Raising awareness to Hospital/MCS staff of the safeguarding learning disability specialist team email address to support patients/service users, parents, carers and their families enquiries.

### **We will demonstrate achieved outcomes through:**

- Quality care round checklists highlighting completion of reasonable adjustment care plans and risk assessments.
- Audit of the use of hospital passports.
- Sharing lessons learnt at clinical and corporate meetings and use it as a tool for improvement.
- Patient, parent, carer and family evaluation and feedback of services through surveys.
- A programme of clinical audit to demonstrate continuous improvement.



## Standard 2 - Inclusion and Engagement

**We will ensure that all patients/service users with learning disabilities and/or autism and their families and carers are empowered to be partners in the care they receive.**

### **We will ensure:**

- Processes are in place that ensure we work and engage with patients/service users receiving care, their families and carers, as set out in the NHS constitution.
- Our services are 'values-led', for example, in service design/improvement, handling of complaints, investigations, training and development and recruitment.
- Relevant services are co-designed with people with learning disabilities and/or autism and their families and carers.
- We learn from complaints, investigations and mortality reviews, and engage with and involve patients, parent, families and carers throughout these processes.
- We empower people with learning disabilities and/or autism, their families and carers to exercise their rights.

### **We will achieve this by:**

- Developing and delivering a specific programme of work within the Trust What Matters To Me (WMTM) Patient Experience Programme to engage people with learning disabilities and/or autism.
- Continuing to work with the MFT Learning Disability and Autism Patient and Carer Forum.
- Raising awareness of Trust values and behaviours throughout the workforce.
- Co-produce services with patients/service users, parents, families and carers.
- Involving those with learning disabilities and/or autism in the delivery of training, sharing their lived experience.
- Merging local policies and guidelines across MFT ensuring clinical practice is safe, effective and standardised.
- Setting standards of care and quality improvements across all Hospitals/MCS/LCOs, to ensure that all patients/families/carers receive high quality safe care in the right place at the right time.
- Raising awareness to Hospital/MCS staff of the safeguarding learning disability specialist team email inbox/helpline to support patient, family and carer enquiries.
- Capturing patient/service user views in clinical assessments.

## **We will demonstrate achieved outcomes through:**

- Representation on the patient and public involvement patient safety subgroup.
- All areas having a Learning Disability Champion.
- Review e-Learning uptake through the learning hub/mandatory training data intelligence.
- Annual education and training updates.
- Attendance at Patient and Carer Forums.
- Specialist learning disability safeguarding nurses leading in specific area's (Quality Care Rounds, LeDeR and Training) and lessons learnt will be implemented and shared with relevant areas, including audits.
- Producing an annual report to demonstrate achievements against this strategy.
- Developing minimum data sets identifying gaps and demonstrating service improvements.
- Audit, evidence of education, completion of action plans.



## Standard 3 - Workforce

**We will have the skills and capacity to meet the needs of people with learning disabilities and/or autism by providing safe and sustainable staffing, with effective leadership at all levels.**

### **We will ensure:**

- The needs of the local population are analysed, and staff have the specialist knowledge and skills to meet the needs of people with learning disabilities and/or autism who access and use our services, as well as those who support them.
- Staff are trained and routinely updated in how to deliver care to patients/service users with learning disabilities and/or autism who use our services, in a way that takes account of their rights, needs and health vulnerabilities; adjustments to how services are delivered and tailored to each patient's/service user's individual needs.
- Workforce plans are in place that manage and mitigate the impact of the growing, cross-system shortage of qualified practitioners with a professional specialism in learning disabilities and/or autism.
- Clinical and practice leadership and consideration of the needs of patients with learning disabilities and/or autism, are demonstrated within local strategies to ensure safe and sustainable staffing.

### **We will achieve this by:**

- Succession planning for learning disability specialist roles to provide leadership and co-ordinate the specialist support and training required for staff.
- Recruit appropriate staff based upon the needs of patients/service users with learning disabilities and/or autism.
- Delivery of learning disability and autism awareness training sessions for all clinical and non-clinical staff, including volunteers.
- Staff understand the health issues associated with patients/service users with learning disabilities and/or autism.
- Learning Disability Champions identified in all areas.
- Staff who are confident and have the skills and knowledge to deliver care with the application of reasonable adjustments and appropriate care planning and risk assessment.

- Staff provide safe, compassionate and individualised care to people with learning disabilities and/or autism.
- Trust wide learning disability and autism training and education at appropriate levels:
  - **Level 1** – e learning mandatory for all staff.
  - **Level 2** – training for unregistered staff who have a patient facing role.
  - **Level 3** – patient facing registered clinical staff (including doctors) with a focus on changing and improving practice.
- Commitment to the provision of high-quality supervision for specialist learning disability safeguarding nurses to support resilience and good practice.
- Supporting new, emerging roles.
- Using patient/service user and carer feedback systems that provide a cohesive mechanism for measuring and monitoring the delivery of care for patients/service users with learning disabilities and/or autism.
- Staff surveys in relation to caring for patients/service users with learning disabilities and/or autism.

**We will demonstrate achieved outcomes through:**

- Feedback and evaluation from teaching sessions delivered across all settings
- Review e-Learning uptake through the learning hub/mandatory training data intelligence.
- Audit, evidence of education, completion of action plans.
- Improved experience for patients/service users with learning disabilities and/or autism, their parents and carers.
- Reduced incidents of harm for patients/service users with learning disabilities and/or autism, their parents and carers.



## Standard 4 - Learning disability services standard

**We will work in partnership with specialist learning disabilities services to fulfil the objectives of national policy and strategy.**

### **Working in partnership we will ensure:**

- We work to develop community-based intensive support, including treatment and support for people accessing mental health services and the criminal justice system.
- Any patient/service user who has been subject to a care and treatment review (CTR) and care and education treatment review (CETR) will be provided with treatments they need and have an assertive approach to discharge planning ensuring no individual stays longer than necessary.
- Processes are in place to regularly review the medications prescribed to people with learning disabilities and/or autism. Specifically, prescribing of all psychotic medication will be considered in line with NHSE's programme Stopping Over Medication Programme (STOMP).
- Clinical pathways are in place that adhere to evidence-based assessment and treatment, time-limited interventions and measurable discharge processes to ensure inpatient episodes are as short as possible.
- Governance processes are in place measuring the use of restraint and other restrictive practices, including detailed evidence-based recommendations to support the discontinuation of planned prone restraints and reduction in unwarranted variation in use of restrictive practices.

### **We will achieve this by:**

- Understanding the knowledge and skills existing within the community as a baseline.
- Undertaking a gap analysis with local partners to determine what can be offered to upskill staff.
- Working with local partners to collaborate and grow services together
- Ensuring areas are aware of CTR and CETR, review treatments provided in line with standards and review documentation utilised to aid staff.

- Liaising with community pharmacies regarding reviews of medication and link in with specialist learning disability safeguarding team.
- Review discharge pathways/documentation and ensure relevant NICE guidelines are adhered to.
- Ensure staff are aware of policies and issue training in areas as required.

**We will demonstrate achieved outcomes through:**

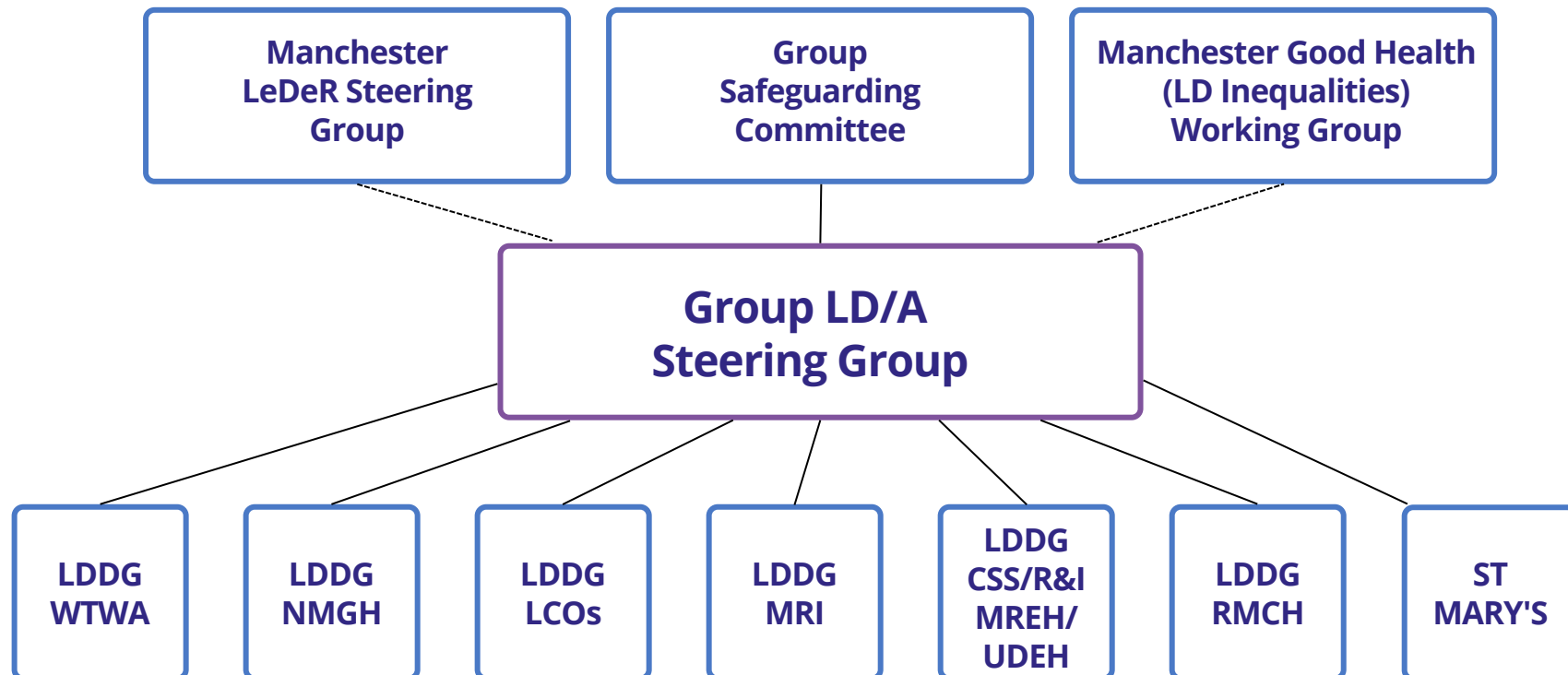
- Availability of advice and support for patients/service users with co-morbidities when needed.
- Raised awareness and training around STOMP
- Community and specialist learning disability safeguarding teams involved in the development of pathways from primary, community, secondary and specialist services and throughout.
- Availability of advice, support and link with mental health teams for training around least restrictive practices.

# 5. Monitoring process

Learning disability and/or autism oversight is provided by the Chair of the MFT Learning Disability Steering Group (Director of Nursing and Professional Lead Manchester and Trafford Local Care Organisations) with executive leadership from the Group Chief Nurse.

Representatives of the MFT Learning Disability Steering Group are responsible for ensuring that the strategy is shared within the hospital/MCS/LCO they represent, and members of the Local Learning Disability Delivery Groups are responsible for ensuring that the strategy is embedded into practice. The progress of the strategy will be monitored regularly by the MFT LD Steering Group and the Group Safeguarding Committee.

## Governance structure





i - [https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability#:~:text=There%20are%201.5%20million%20people,for%20National%20Statistics%20\(2019\)](https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability#:~:text=There%20are%201.5%20million%20people,for%20National%20Statistics%20(2019))

ii - The national strategy for autistic children, young people and adults 2021-2026

iii - <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>

iv - <https://www.mentalhealth.org.uk/cy/node/1923#:~:text=People%20with%20autism%20can%20also,learning%20disabilities%20have%20an%20ASD.>

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

vi - <https://www.england.nhs.uk/learning-disabilities/about/resources/the-learning-disability-improvement-standards-for-nhs-trusts/>

vii - <https://www.mencap.org.uk/learning-disability-explained/what-learning-disability>

viii - <https://www.autism.org.uk/advice-and-guidance/what-is-autism>

ix - <https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

x - <https://www.legislation.gov.uk/ukpga/2009/15/contents>

xi - <https://www.gov.uk/government/news/fulfilling-and-rewarding-lives-the-strategy-for-adults-with-autism-in-england>

xii - <https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf>

xiii - Learning Disabilities Mortality Review (LeDeR) Programme (2015)

xiv - <https://www.gmhsc.org.uk/wp-content/uploads/2018/09/GM-Learning-Disability-Strategy-FINAL.pdf>



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