





Learning Disability and Autism Strategy 2022-2025

The Royal Orthopaedic Hospital



Introduction

This strategy sets out the strategic vision for The Royal Orthopaedic Hospital NHS Foundation Trust (ROH), outlining how patients with learning disabilities or autistic patients can access high quality care with positive health outcomes within the ROH.

This document aims to build on the progress that has been seen since the introduction of the Learning Disability Strategy in 2017 as well as reiterating the commitment of the Trust's board to the ongoing development and improvement of the learning disability and autism service.

This updated strategy will encompass autism alongside learning disabilities in line with the Learning Disability Improvement Standards (NHS Improvement, 2018) and the Learning from lives and deaths – people with a learning disability and autistic people (LeDeR) Policy (2021). Valuing People (2001) outlined the four key principles of choice, rights, independence, and inclusion which should underpin good quality care for people with learning disabilities.

In line with the above, responsibilities outlined in the Equality Act (2010), the Learning Disability Improvement Standards (2018) and the Trust values, the Royal Orthopaedic Hospital must ensure that services are accessible with reasonable adjustments being made. The Trust provides a specialist learning disability service which also offers support for autistic patients.

This strategy aims to identify that this cohort of patients have a wide and varying range of needs, requiring a flexible and personalised approach and through application of the principles of learning disability practice and appropriate adjustments equal access to good quality care can be achieved.

This strategy was developed collaboratively with input from patients, parents/ carers and staff, as well as demonstrating that key reports, lessons learned and examples of best practice have been acknowledged to provide a clear framework for the delivery of the best quality care.



Context

There are approximately 1.5 million people with a learning disability in the UK (ONS, 2020; PHE, 2020) and approximately 700,000 people diagnosed with autism (National Autistic Society, 2018). Within the West Midlands there are 23,800 (2.3%) people registered as having a learning disability (Office for National Statistics, 2011), with 60,000 people diagnosed with autism (Autism West Midlands, 2021).

As a Trust we offer services for children, young people, and adults, with those aged 16 and above being admitted for procedures. The Trust also employs people with a learning disability with staff being encouraged to share diagnoses and needs to receive appropriate support.



The most recent LeDeR (Learning from Lives and Deaths) Annual Report published in July 2022 identified that men with a learning disability die 22 years sooner than the general population, and women 26 years sooner. People with learning disabilities are more likely to die from an avoidable premature death due to healthcare inequalities where needs have been unmet or unrecognised (LeDeR Annual Report, 2022). This is even greater for those from a minority ethnic background, so diversity of needs must be taken into consideration when providing a service (LeDeR Annual Report, 2021).

Autistic people have poorer health outcomes than that of the general population and face health and care inequalities (HM Government, 2021).

People with learning disabilities are more likely to be affected by a number of health conditions or co-morbidities, or experience diagnostic overshadowing (SUDEP Action, 2020; Emerson and Baines, 2011). People with learning disabilities are more vulnerable in acute hospitals than the general population (NPSA, 2004).

The Department of Health have found that when people with a learning disability or autism are admitted to NHS Trusts, staff demonstrate a lack of confidence, lack of knowledge and skills, lack of understanding and the patient is often segregated away from patients who do not have additional needs (DOH, 2019).

People with learning disabilities and/ or autism must have the same equal access to high quality, responsive healthcare as the rest of the population that is free from discrimination with barriers to care removed (Equality Act, 2010; Convention on the Rights of Persons with Disabilities, 2006).

Definitions

What is a learning disability?

A learning disability is an impairment of the brain starting before adulthood which affects development and causes a significantly reduced ability to understand complex information or learn new skills (Valuing People, 2001).

It means that an individual has a reduced intellectual ability and difficulty with everyday activities that affects someone for their whole life. This impairs social functioning and means that the person may have difficulty completing activities of daily living.

The level of support someone may require varies widely as a learning disability can be classed as mild, moderate, severe or profound. It is important to remember that with the right support an individual with a learning disability can live an independent life (Mencap, 2020).

All people with a learning disability should be on their GP's learning disability register, ensuring they have an annual health check.

What is autism?

Autism is a lifelong developmental condition affecting how a person may communicate and interact with other people and the world around them. Autism is often referred to as a spectrum with every individual having different strengths, struggles, needs and will experience the world differently (HM Government, 2021; National Autistic Society, 2021). Autistic people may prefer to be referred to as neurodiverse, an increasingly common term covering a range of neurological conditions.

This strategy will also cover autism as it is widely recognised that healthcare services can do more to support autistic patients in line with recently published policies and guidance.

The NHS Long Term Plan (2019), NHS Learning Disability Improvement Standards (2018) and LeDeR policy (2021) have all recognised the importance of autism being included alongside learning disabilities. Whilst they are very different and varied diagnoses, the support offered is similar as individualised care is required with appropriate reasonable adjustments being made.

What is a learning difficulty?

A learning difficulty is not a learning disability. A learning difficulty does not affect intellect, with strategies and tools used to make the processing of information or managing situations more easily (Mental Health Foundation, 2021). Examples of a learning difficulty include dyslexia, dyspraxia or ADHD.

The Learning Disability Strategy 2017-2020

Since the learning disability strategy was implemented in 2017 there have been several improvements in learning disability care across the Trust, which was echoed by the 2018 CQC report.

- Mandatory awareness training was introduced, both online and face to face with 78% of staff attending learning disability and autism awareness training by 2022
- The Trust signed up to the annual benchmarking project in conjunction with NHS England (NHSE) and NHS Improvement (NHSI) to measure Trusts performance against the Learning Disability Improvement Standards
- Introduction of hospital passports
- Introduction of the internal learning disability notification system for staff to submit following contact with a patient
- Specialist support given for appointments and admissions
- Introduction of a basic recording system with the view to develop a database
- Implementation of reasonable adjustments e.g. first appointments

There is work outstanding which will be encompassed into this updated strategy:

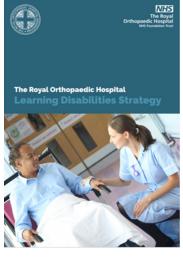
- Rollout of regular face to face forums
- Information leaflet for patients
- Communication boxes for all wards and department areas
- Readily available easy read information
- Patient feedback survey

Development of The Learning Disability

To update the strategy, a staff audit was carried out in April 2021 in a questionnaire format which was completed by 82 members of ROH staff. As well as this, during learning disability week 2022 staff were asked to make suggestions regarding changes they would like to see within the service. Data collated from these inform the priorities and actions laid out in this strategy.

To ensure the patient voice was heard and implemented throughout the strategy, a survey was sent out to patients to complete. The responses were analysed and reflected within the priorities and actions.

Data was also used from the annual benchmarking report published by NHS England and NHS Improvement showing how the Trust performs against the Learning Disability Standards. This includes a patient and a staff survey as well as organisational level data collection.



Reasonable adjustments suggested by the ROH team

- Facilitating visit prior to TCI
- Admitting early
- Combining appointments / procedures
- Appropriate equipment available
- First / last appointment
- Meeting with staff involved
- Longer appointment times
- Offering adapted options
- Quiet waiting place
- Accompanying parent / carer
- Adapting communication
- Adjusting environment

Feedback

We're committed to ensuring the voice of our patients help to drive our strategy development and service delivery.

"Outstanding care! She had an extremely positive experience. It's so important that staff understand learning disabilities or complex needs"

Carer of a patient with learning disabilities, July 2021

"Staff actually listened and made the adjustments needed for his autism."

Parent of a patient with learning disabilities, December 2021

"The support has been invaluable!"

Parent of a patient with learning disabilities, November 2021

"The service offered is amazing and I've never had this kind of support elsewhere."

Patient with Asperger's, February 2022

"It has been fantastic at the ROH and we really appreciate the support."

Parent of an autistic patient, December 2021

"Thank you so much for looking after me, you are amazing"

Autistic patient, February 2022

"He was treated with such kindness and dignity"

Family member of a patient with learning disabilities, July 2022

The goals of our strategy









Goal	How it will be achieved	How will it be monitored
We will provide outstanding care	 Ensure the patient is at the centre of every decision regarding their care Involve important people around the individual in decision making Increase awareness and use of hospital passports Increase awareness, understanding and implementation of reasonable adjustments Communication strategies and appropriate assessments will be used Learning disability notifications will be submitted following contact Forward-looking document used to proactively plan Development of a 'reasonable adjustments flag' by NHS Digital Smooth detailed handover and discharge Development of a learning disability database Ensure effective safeguarding arrangements are in place to ensure any restrictions placed on a patient are proportionate, necessary and regularly reviewed 	 Bimonthly Safeguarding Committee Annual learning disability audit Annual benchmarking project Patient Engagement and Experience Group
We will always listen	 Face to face learning disability and autism forum to be launched Patient and parent/carer feedback to be gathered proactively Involvement of experts by experience in training delivery Information leaflets about the learning disability service to be developed Easier access to easy read information Learn from excellence and best practice 	 Bimonthly Safeguarding Committee Patient Engagement and Experience Group Annual benchmarking project
We will have the skills	 All staff to attend mandatory learning disability and autism training sessions Mandatory autism e-learning to be added on ESR Training to be regularly reviewed and updated to reflect new guidance and best practice The ROH is committed to rolling out the Oliver McGowan Mandatory Training in Learning Disability and Autism once it has been developed Staff to utilise the ROH Hub and access information, support and 'how to' guides 	 Bimonthly Safeguarding Committee Annual benchmarking project Annual learning disability audit
We will build positive partnerships	 Appropriate sharing of information between departments Partnership working between services Tailor relationships with patients to support them effectively Collaboratively work as part of a multidisciplinary team Appropriate support available for staff 	 Annual learning disability audit

Next steps

Communicating our strategy

A one-page summary will be launched alongside the strategy to allow for ease of reference. There will be an action plan reflecting the actions laid out in the strategy outlining the steps and realistic timeline to achieve them.

Aligning our strategy

This strategy will align with the Learning Disability Improvement Standards and corresponding action plan to demonstrate commitment to the implementation and development of improved services for patients with learning disabilities or autistic patients.

Measuring outcomes

Outcomes against these standards will be measured by the annual benchmarking project, with recommendations feeding back into the service.

Annual review

This strategy is an evolving plan which will be formally reviewed annually to ensure it is fit for purpose with further actions or steps to achieving our priorities and actions being identified if required. Commitment and effective implementation will also be measured through annual audit.

Maintaining progress

To ensure effective rollout and monitoring of progress quarterly reporting and review will be conducted at the Trust's Safeguarding Committee. The Trust board will also be kept up to date through upward report via the Trust Quality and Safety Committee.

Useful resources

nhs.uk/conditions/learning-disabilities nhs.uk/conditions/autism easyhealth.org.uk

How to find support

roh.learningdisability@nhs.net



References

- Autism West Midlands (2021) Autism Awareness. [pdf] Available at: https://autismwestmidlands.org.uk/wp-content/uploads/2021/03/Autism_Awareness_Infographic_Mar_2021.pdf
- Emerson and Baines (2011) Health inequalities and people with learning disabilities in the UK. Tizard Learning Disability review, 16(1), pp.42-48
- Department of Health and Social Care (2019) Learning disability and autism training for health and care staff [pdf] Available at: https://assets.publishing.service.gov.uk/government/uploads/ system/uploads/attachment_data/file/778129/Learning_disability_and_autism_training_for_ health_and_care_staff_consultation_document.pdf
- Department of Health (2001) Valuing People [pdf] London: DoH. Available at: <u>5086.pdf</u> (publishing.service.gov.uk)
- HM Government (2021) The national strategy for autistic children, young people and adults: 2021
 2026. London: HM Government
- HM Government (2010) The Equality Act. London: The Stationery Office.
- LeDeR. Learning from lives and deaths People with a learning disability and autistic people (2022) Annual Report 2021 [pdf] London: Kings College London. Available at: leder-main-report-hyperlinked.pdf (kcl.ac.uk)
- The Learning Disabilities Mortality Review (LeDeR) Programme (2021) Annual Report 2020 [pdf]
 Bristol: The University of Bristol. Available at: https://leder.nhs.uk/images/annual_reports/
 LeDeR-bristol-annual-report-2020.pdf
- Mencap (2020) What is a learning disability? Available at: What is a learning disability? | Mencap
- Mental Health Foundation (2021) Learning disabilities. Available at: https://www.mentalhealth.org.uk/cy/node/1955
- National Autistic Society (2021) What is autism? Available at: what is autism
- National Health Service (2019) The NHS Long Term Plan. [pdf] v.1.2. Available at: NHS Long Term Plan v1.2 August 2019
- National Patient Safety Agency (2004) Understanding the Patient Safety Issues for People With Learning Disabilities. London: NPSA
- NHS England and NHS Improvement (2021) Learning from lives and deaths People with a learning disability and autistic people (LeDeR) policy 2021. [pdf] Available at: <u>B0428-LeDeR-policy-2021.pdf</u> (england.nhs.uk)
- NHS Improvement (2018) The learning disability improvement standards for NHS trusts. [pdf]
 v.1.17. Available at: v1.17_Improvement_Standards_added_note.pdf (england.nhs.uk)
- Public Health England (2020) People with learning disabilities in England. Available at: <u>People</u> with learning disabilities in England GOV.UK (www.gov.uk)
- Care Quality Commission (2018) The Royal Orthopaedic Hospital NHS Foundation Inspection report. Available at: <u>Provider section - RRJ The Royal Orthopaedic Hospital NHS Foundation Trust</u> (23/01/2018) INS2-4488069930 (cqc.org.uk)
- Office for National Statistics (2020) Estimates of the population for the UK, England and Wales, Scotland and Northern Ireland. Available at: <u>Estimates of the population for the UK, England and Wales</u>, Scotland and Northern Ireland - Office for National Statistics (ons.gov.uk)
- SUDEP Action (2020) Urgent call for action as learning disability mortality report has epilepsy
 in the spotlight. Available at: <u>Urgent call for action as learning disability mortality report has
 epilepsy in the spotlight | SUDEP Action</u>
- United Nations (2006) Convention on the rights of persons with disabilities. [pdf] London: The Stationery Office. Available at: Convention on the Rights of Persons with Disabilities CM 7905 (publishing.service.gov.uk)

