



# Learning Disability and Autism Strategy September 2019

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## **1. Introduction**

- 1.1 This strategy demonstrates the Trust's on-going commitment to improving the care and treatment of people with Learning Disabilities, Autism or both when accessing University Hospitals Birmingham (UHB) NHS Foundation Trust services. We will be working in partnership with other Trusts in the West Midlands, other statutory organisations, third sector and voluntary organisations and charities, to ensure that our strategy is at the forefront of the latest information available in the care of this patient group.
- 1.2 This strategy sets out the Trust's commitment in line with the National Standards. It identifies the strategic priorities (high level statements/objectives intended to deliver the vision), a high-level plan (the things we will need to do to meet the strategic objectives) and is supported by an operational / implementation plan which details the tangible actions, resources and timings for delivering the strategy.

## **2. Vision**

- 2.1 The Trust's vision of 'Building Healthier Lives' is as relevant in relation to patients with a Learning Disability as it is for any other patient. People with Learning Disabilities, Autism or both have the right to the same level of healthcare as that provided to the general population and care should be flexible and responsive.

- 2.2 Within the Trust's Vision, this strategy will:

*'Improve the health and wellbeing of people with learning disabilities, autism or both who access UHB services, working in partnership with people with a Learning Disability, Autism or both, their families and carers and the local community.'*

## **3. Our Purpose**

- 3.1 Our purpose is to improve the health of our Learning Disability, Autism or both patients and communities through delivering the best in clinical care, research, innovation and education by adopting Trust values of Collaboration, Honesty, Accountability, Innovation and being Respectful.
- 3.2 Based on the above, this strategy document provides UHB with a firm basis for delivering high quality, safe, person centred care, which provides people with Learning Disability, Autism or both, and their carers, with the most positive experience possible. This means supporting the needs of our patients with a Learning Disability, Autism or both ensuring that they are treated at the right time, in the right place, by the right professional resulting in the best clinical outcome.

## 4. Aims

### 4.1 The main aims of this strategy are to:

- Set out the principles and framework of the management of patients with a Learning Disability, Autism or both and their carers. This strategy will include an 'Easy Read' version to support patient engagement with the strategy.
- Set out the governance and audit requirements to ensure assurance of the effective management of patients with a Learning Disability, Autism or both.
- Ensure staff to have clear competencies, to be competent and confident, of the needs of people with a Learning Disability, Autism or both and to equip them to deal more effectively with the particular needs of the individual by providing appropriate adaptations and adjustments.
- Learn from the national and strategic context to inform the Trust's approach to the long-term planning and service provision for people with Learning Disabilities autism or both and their carers in line with National Standards.

### 4.2 In this strategy the term 'Learning Disability, Autism or both' has been adopted. The terms are used throughout this strategy to ensure distinction from the broad range of learning difficulties and is referencing the NHS website and National Autism Society definitions:

*A learning disability affects the way a person learns new things throughout their lifetime, the way a person understands information and how they communicate. This means they can have difficulty:*

- *understanding new or complex information*
- *learning new skills*
- *coping independently*

*A learning disability can be mild, moderate or severe. (NHS, 2019)*

*Autism is a lifelong developmental disability that affects how people perceive the world and interact with others (National Autism Society, 2019)*

## 5. National Context

### 5.1 There are approximately 862,995 adults of working age with a Learning Disability (LD) in the UK and approximately 347,013 children; people with an LD make up over 2% of the population. The number of people with severe learning disabilities has been predicted to grow by approximately 1% a year due to:

- Increased life expectancy, especially in people with Down's syndrome
- Growing numbers of children and young people with complex and multiple disabilities who now survive into adulthood
- A sharp rise in the reported numbers of school age children with autistic spectrum disorders, some of whom will have learning disabilities;

- Greater prevalence among some minority ethnic populations of South Asian origins
- 5.2 Many people with learning disabilities need additional support and services throughout their lives meaning more intense and longer involvement with public services, including health.
- Department of Health, 2001
- 5.3 NHS improvement produced Learning Disability Improvement Standards in June 2018 as some people with learning disabilities, autism or both, encounter difficulties when accessing NHS services and can have much poorer experiences than the general population. The standards provide a benchmark against which Trusts can measure performance and drive quality improvement. The four standards concern:
- Respecting and protecting rights
  - Inclusion and engagement
  - Workforce
  - Specialist learning disability services
- NHSI, 2018
- 5.4 More widely, the NHS has developed a Long Term Plan to set out what the priorities are over the next ten years and Learning Disability and Autism are included in this. The Trust is also involved in the Learning Disabilities Mortality Review (LeDeR) Programme, commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the overall aims are to:
1. Support improvements in the quality of health and social care service delivery for people with learning disabilities, and
  2. Help reduce premature mortality and health inequalities for people with learning disabilities.
- 5.5 Our strategy, work and activities at the Trust will directly support the work of the Learning Disability Programme Board, the Transforming Care mandate commitment and LeDeR.

## 6. Where Do We Want To Be?

### **The Principles and Framework for the Management of Patients at UHB**

- 6.1 This framework for the management of this patient group at the Trust is guided by the National Standards for the provision of care for our patients with a Learning Disability, Autism or both.
- 6.2 The Learning Disability Standards have been developed with a number of outcomes created by people with Learning Disability and their families. The Strategic Priorities shown below, incorporate the requirements of the Adult Autism Strategy. These clearly state what is expected from the NHS. By taking this approach to quality improvement, it places patient 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.

6.3 There are four standards:

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

6.3.1 These standards incorporate the requirements of the Adult Autism Strategy, such as access to services, reasonable adjustments and training. However, the Trust will carry out a further gap analysis, based on the ‘*Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy*’ (Dept of Health, 2015), to assess its response specifically to patients with a sole diagnosis of Autism.

Our commitment to each standard is shown below; *reference numbers correlate with operational plan reference numbers:*

### 1. Respecting and Protecting Rights

**The Trust will ensure that it meets their Equality Act Duties to patients with learning disabilities, autism or both, and that the wider human rights of these patients are respected and protected, as required by the *Human Rights Act*.**

Ref No.	Strategic Priorities	High Level Plan
1.1	We will demonstrate reasonable adjustments to care pathways to ensure patients can access highly personalised care and achieve equality of outcomes.	Including: <ul style="list-style-type: none"> <li>• using modified communication</li> <li>• flexible appointment systems</li> <li>• modified triage assessments</li> <li>• ensuring due regard to the content of hospital passports or All About Me booklets</li> <li>• evaluate our learning to improve care pathways.</li> </ul>
1.2	We will have mechanisms to identify and flag patients with learning disabilities, autism or both from the point of admission through to discharge; and will share this information as people move through departments / divisions and between services.	Including: <ul style="list-style-type: none"> <li>• Use of electronic flags in patient administration systems</li> <li>• Ensuring the necessary reasonable adjustments are recorded in a patient’s notes</li> <li>• Auditing on continuity of care</li> </ul>
1.3	We will have in place processes to investigate the death of a person with learning disabilities, autism or both while using our services, and learn lessons from the findings of these investigations.	Including: <ul style="list-style-type: none"> <li>• Local investigations</li> <li>• Full engagement with the national LeDeR programme</li> <li>• Acting to address findings of investigations.</li> </ul>

1.4	We will demonstrate that we vigilantly monitor any restrictions or deprivations of liberty associated with the delivery of care and treatment.	<p>Including:</p> <ul style="list-style-type: none"> <li>• Having arrangements to ensure any restrictions and deprivations of liberty are correctly and lawfully authorised</li> <li>• Having routine checks to ensure restrictions /deprivations are always necessary and proportionate.</li> <li>• Ensuring transparency about what we do and why</li> <li>• Being open to challenge.</li> </ul>
1.5	We will have measures and measurement to promote anti-discriminatory practice.	<p>Including:</p> <ul style="list-style-type: none"> <li>• Have effective safeguarding arrangements to ensure that diagnostic overshadowing and value judgements about a person's quality of life do not detract from their care.</li> <li>• Compare outcomes and experiences of people with learning disabilities, autism or both with those of non-disabled peers.</li> </ul>

## 2. Inclusion and Engagement

**The Trust will ensure that all patients with learning disabilities, autism or both and their families and carers are empowered to be partners in the care they receive.**

Ref No	Strategic Priorities	High Level Plan
2.1	We will demonstrate processes that ensure we work and engage with patients receiving care, their families and carers, as set out in the NHS Constitution.	<ul style="list-style-type: none"> <li>• We will involve patients, families and carers in all aspects of planning their care</li> <li>• We will involve patients, families and carers in evaluating their care and treatment</li> <li>• We will use feedback and experiences to improve services.</li> <li>• We will tell people if their care has raised safety concerns and what will be done to prevent recurrences.</li> </ul>
2.2	We will demonstrate that our services are 'values-led'; for example, in service design/improvement, handling of complaints, investigations, training and development, and recruitment.	<p>We will ensure that the Trust:</p> <ul style="list-style-type: none"> <li>• Makes clear the attitudes, behaviours and communication they expect from their staff</li> <li>• Supports people whose complaints and concerns are being looked into</li> <li>• Involves people with learning disabilities in staff recruitment.</li> </ul>
2.3	We will demonstrate that we codesign relevant services with people with learning	<p>This includes:</p> <ul style="list-style-type: none"> <li>• Involvement of patients, families and</li> </ul>

	disabilities, autism or both and their families and carers.	<p>carers in reviewing services/pathways that affect them and planning improvements</p> <ul style="list-style-type: none"> <li>• Ensure that patients with learning disabilities, autism or both are fully involved in strategic decision making and designing approaches to continuous learning.</li> </ul>
2.4	We will demonstrate that we learn from complaints, investigations and mortality reviews, and that we engage with and involve patients, families and carers throughout these processes.	<p>Including:</p> <ul style="list-style-type: none"> <li>• Adopting NHS England’s initiative ‘Ask Listen Do’.</li> <li>• In line with the LeDeR reviews, we will invite the input of patients and families affected, to maximise learning from untoward events.</li> </ul>
2.5	We will demonstrate that we empower people with learning disabilities, autism or both and their families and carers to exercise their rights.	<p>Including:</p> <ul style="list-style-type: none"> <li>• Considering commissioning people with learning disabilities, autism or both to independently review services, and paying them for any work they do.</li> <li>• Actively informing patients of their rights, in a manner that is meaningful to them</li> <li>• Supporting the use of Independent Mental Capacity Advocates (IMCA).</li> </ul>

### 3. Workforce

**We will have the skills and capacity to meet the needs of people with learning disabilities, autism or both by providing safe and sustainable staffing, with effective leadership at all levels. The commitment to training is shown in paragraph 10.**

Ref No	Strategic Priorities	High Level Plan
3.1	We will analyse of the needs of the local population, we will ensure staff have the specialist knowledge and skills to meet the needs of people with learning disabilities, autism or both who access and use our services, as well as those who support them.	<p>We will:</p> <ul style="list-style-type: none"> <li>• Understand patterns of local need among patients with learning disabilities, autism or both</li> <li>• Use this knowledge to determine what skills are required</li> <li>• Recruit the right staff in the right numbers.</li> </ul>
3.2	Staff will be trained and then routinely updated in how to deliver care to patients with learning disabilities, autism or both who use our services, in a way that takes account of their rights, needs and health vulnerabilities; adjustments to how services are delivered will be	<p>Including ensuring staff have been trained in:</p> <ul style="list-style-type: none"> <li>• Learning disabilities and autism awareness</li> <li>• Health issues associated with learning disabilities</li> <li>• Supporting people with challenging needs</li> </ul>



	tailored to each patient's individual needs.	<ul style="list-style-type: none"> <li>• Human rights and</li> <li>• Mental capacity and best interests</li> </ul>
3.3	We will have workforce plans that manage and mitigate the impact of the growing, cross-system shortage of qualified practitioners with a professional specialism in learning disabilities.	<p>Including:</p> <ul style="list-style-type: none"> <li>• Supporting new, emerging roles and</li> <li>• Utilising experts by experience/peer workers</li> <li>• Workforce Strategy in place</li> </ul>
3.4	We will demonstrate clinical and practice leadership and consideration of the needs of patients with learning disabilities, autism or both, within local strategies to ensure safe and sustainable staffing.	<p>Including:</p> <ul style="list-style-type: none"> <li>• Having a designated lead for learning disabilities</li> <li>• Providing induction, mentorship and supervision that explore how people with learning disabilities, autism or both are being supported.</li> </ul>

#### 4. Specialist Learning Disability Services

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

Ref No	Strategic Priorities	High Level Plan
4.1	We will work in partnership with Trusts' plans for the development of community-based intensive support, including treatment and support for people accessing mental health services and the criminal justice system.	We will agree collaborative and co-ordinated joint working arrangements with local partners.
4.2	We will work in partnership with Trusts to ensure that any patient admitted from that Trust has been subject to a care and treatment review (CTR) and care and education treatment review (CETR). This will assist in providing the treatments that are needed and have an assertive approach to discharge planning ensuring no individual stays longer than necessary.	We will support Trusts in fully complying with the national standards for CTRs and CETR; providing the treatments that are needed and having an assertive approach to discharge planning.
4.3	We will have processes to regularly review the medications prescribed to people with learning disabilities, autism or both. Specifically, prescribing of all psychotropic medication should be considered in line with NHS England's programme STopping Over Medication Programme (STOMP).	<p>We will engage with the STOMP programme to ensure that the Trust:</p> <ul style="list-style-type: none"> <li>• Utilises specialist practitioners to contribute to medication reviews.</li> <li>• Considers a person's past experience of adverse reactions and their preferences, including psychosocial alternatives to medication</li> <li>• Will provide the right support when a patient's medication is reduced</li> <li>• We will audit quarterly on the use of psychotropic medication.</li> </ul>
4.4	We will have clinical pathways that	We will ensure that there are clear discharge

	adhere to evidence-based assessment and treatment, time-limited interventions and measurable discharge processes to ensure inpatient episodes are as short as possible.	pathways, which are initiated on admission and shared with patients and their families. It also means National Institute for Health and Care Excellence (NICE) guidelines are appropriately applied to patients with learning disabilities, autism or both.
4.5	We will have governance processes for 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 demonstrate that alternative approaches are being used.	We will have policies and procedures in place.  Staff are trained in understanding the limitations of restraint.  Data on restrictive interventions is collected, analysed and utilised within the Trust.

## 7. Where Are We Now?

7.1 The Trust is committed to ensuring high quality care for all of our patients, including those with a Learning Disability, Autism or both. Therefore, it is acknowledged that the Trust carries out positive care management of this patient group, with this strategy aiming to structure, improve and refine approaches across the Trust, to achieve consistency.

7.2 In order to establish a baseline for the Trust in support of actions to achieve improvement, an internal and external benchmarking approach will be undertaken to establish:

- How well current services and resources are working for people with learning disabilities
- Current and future demand for support
- Financial context
- Other threats and opportunities from new legislation and policy

### 7.2.1 External:

The Trust will seek support in the use of, or utilise the principles of, the NHS Quality Checkers Programme developed by NHS England who has worked with people with a learning disability, their families, carers and self-advocacy groups to identify a number of areas that are particularly important to the health of those with a learning disability. NHS Quality Checkers assess the service by: talking to staff and patients; watching what happens within the service; reading what the staff say about the service; listening to patients and their families / carers. This assessment is based on 4 Standards:

- Standard 1. I am involved in my care at all times.

- Standard 2. My care, treatment and support is planned to meet my needs. Or in an emergency the hospital can access information about me.
- Standard 3. I get good care and feel safe.
- Standard 4. I get good care from a service that has trained staff that know how to do their job well and are always looking to improve.

### 7.2.2 Internal:

The Lead Nurse for Older Adults is responsible for the management of the care of patients with a Learning Disability, Autism or both. They will arrange and support the benchmarking of services across the Trust, to provide on-going feedback, recommendations and, as appropriate, advice and guidance, regarding the implementation of the principles of care for the patient group within services.

## 8. How Do We Get To Where We Want To Be / How Do We Know How Well We're Doing?

- 8.1 An operational / implementation plan has been created which identifies the standards, those measures / actions required to meet them, the owner of the action, the implementation date and the assurance required to measure and evidence completion.
- 8.2 This document is to be read in conjunction with the strategy and is intended to be a working document, managed in accordance with the governance arrangements shown in section 9 of this strategy.

## 9. Governance and audit requirements

### 9.1 Governance

9.1.1 The Trust's performance in meeting the standards set out for the care of patients with a Learning Disability, Autism or both are examined and reported through a series of meetings and reports. The Trust Board gains assurance that the standards expected are being delivered through quarterly Care Quality Committee reports and an annual report.

9.1.2 These meetings comprise:

**Extra Vulnerability Steering Group** (Learning Disability, Autism, Delirium and Dementia) - Monthly meeting chaired by the Deputy Chief Nurse.

Reviews:

- strategy delivery plans,
- commissions audits,
- reviews training compliance,
- reviews lessons learnt, best practice identified and complaints,
- outcome of LeDeR reviews within the Trust,
- Receives recommendations / conclusions from other reports / fora / NICE guidance

**Safeguarding Board** – monthly meeting chaired by Executive Chief Nurse  
This meeting will receive from the Extra Vulnerability Steering Group:

- minutes,
- relevant cases to be discussed, and
- outcome of LeDeR reviews

**Quarterly report to Care Quality Committee** – quarterly meeting chaired by the Executive Chief Nurse

Reporting, by exception, on the above performance of the delivery of this strategy / operational / implementation plan covering:

- Assurances from this strategy and areas where further assurance is being or requires action will result from its delivery, learning gained and managing any risk.

**Trust Board** – annual report to the Trust Board on the performance of the strategy to provide assurance.

## 9.2 Audit

Key to ensuring that the Trust's commitment to the strategy is in evidence across the organisation will be assessed from quarterly audits of how services engage with, and improve practice from, the requirements of the strategy.

## 10. Training and Education –

Ensuring staff develop a better understanding of, competence in, and confidence when, caring for patients with a learning disability autism or both, and to equip them to deal more effectively with the particular needs of the individual.

- 10.1 The delivery of learning disabilities services involves a person centred, risk-based workforce that is extensive and diverse, including many staff closely engaged in providing care as well as offering information, education, support and assistance.
- 10.2 We will deliver the Learning Disabilities Core Skills Education and Training Framework (2015-16) which was commissioned by the Department of Health and developed in collaboration by Skills for Health, Skills for Care and Health Education England.
- 10.3 This framework will be reviewed within the Trust in order to utilise those components most relevant to our services, which will be integrated into our training programmes. Additional learning outcomes may be locally determined to meet education and training needs in specific settings e.g. according to our local context, risk assessment or policy.
- 10.4 The core skills and knowledge described in the framework are defined at 3 tiers:
  - Tier 1 knowledge for roles that require general awareness of learning disabilities

- Tier 2 knowledge and skills for roles that will have some regular contact with people (children, young people and adults) with a learning disability
- Tier 3 knowledge and skills for those providing care and support for people (children, young people and adults) with a learning disability

10.5 The framework will:

- Standardise the interpretation of learning disabilities education and training, and guide the focus and aims of learning disabilities education and training delivery
- Continue to review the educational relevance of learning disabilities training
- Improve the quality and consistency of education and training provision; this being evaluated from staff, patients and carers.

10.6 The framework also supports the assessment of competence, training needs analysis and provision of minimum standards of performance within performance management systems (e.g. as part of supervision or appraisal).

## **11. Future Planning**

11.1 Learning from the national and strategic context to inform the Trust's approach to the long-term planning and service provision for people with Learning Disabilities autism or both and their carers in line with National Standards, the Trust will:

- Monitor reports, guidance and best practice published in support of improving the care of patients with a Learning Disability, Autism or both.
- Take cognisance of the recommendation, conclusions and outcomes of reviews, including those received from LeDeR
- Evidence that we are a learning organisation and act on outcomes of reviews.

## **References**

- The learning disability improvement standards for NHS trusts (NHS Improvement June 2018) June 2018
- Learning Disabilities Core Skills Education and Training Framework (Health Education England), 2015-16
- Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy (DoH March 2015)
- NHS Quality Checkers Programme (NHS England June 2018)
- National Autism Society, 2019
- NHS website, 2019