Learning Disability Strategy
2020 - 2022
Our equality statement

"To ensure we remain focused on equality of outcome and purpose. Equality, Diversity, Inclusion and Human Rights encompass all our aims, objectives and actions addressing inequalities and promoting diversity in healthcare and employment.

The key principle of diversity and inclusion is that it belongs to everyone and that every individual has the right to be treated with respect and dignity as aligned to our core values.

We will ensure that our services are anti-discriminatory enabling equality of access and provision and meeting the legal requirements under the Equality Act 2010 and the specific elements of the Public Sector Equality Duty. We will use the Equality Delivery System 2 to ensure that our service priorities are influenced and set by the health needs of all our local and regional communities through consultation, equality, monitoring and partnership working.

We will demonstrate “due regard” in all aspects of our business.”
Introduction

“People with learning disabilities and/or autism and their families have an array of rights in law or Government policy - through human rights law, the Equalities Act, the NHS constitution, the Mental Health Act, the Care Act, the Mental Capacity Act, the UN Convention on the Rights of Persons with Disabilities, and so on… [but] the lived experience of people with learning disabilities and/or autism and their families is too often very different. Too often they feel powerless, their rights unclear, misunderstood or ignored.”

(Winterbourne View – Time for Change) (1)

There are currently over one million people with a learning disability living in the UK (learning disability prevalence rates, Learning Disabilities Observatory, People with learning disabilities in England 2015) (2). There are 347,000 children with a learning disability (aged between 0-17) in the UK. This equates to 2% of adults and 2.5% of children in the UK.

People with learning disabilities die, on average 15-20 years sooner than people without a learning disability, with some of those deaths identified as being potentially amenable to good quality healthcare (The Learning Disabilities Mortality Review (LeDeR) Programme 2018) (3). This equates to approximately 1,200 people with a learning disability dying avoidably every year.

The purpose of this document is to set out East of England Ambulance Service NHS Trust's (EEAST) three-year strategy for improving care and experience for people living with a learning disability, autism, or both, who use our services.

It will support a wider overarching desire to ensure that people with learning disabilities, autism, or both, and their families and carers should be able to expect high quality care across all services provided by the NHS (NHS England (NHSE), NHS Long Term Plan. 2019) (4). They should receive treatment, care and support which is safe and person centred; and is able to be accessed with parity in line with their non-disabled peers.

We recognise and welcome the opportunity to work in partnership with health and social care statutory care providers and voluntary agencies, as well as our local clinical commissioning groups. The overarching goals outlined within the NHS Equality Delivery System 2 (EDS2) (5) underpins the ethos of this document and supports the NHS constitution statement that “everyone counts”.

These collaborations will aid and support our work and contribute to improving the health and outcomes of those with learning disabilities, and their careers, living within our area.

This strategy is informed by national guidance on delivering care to persons living with learning disabilities, autism or both and their families and carers.
Background

Mencap define a learning disability as “A reduced intellectual ability and difficulty with everyday activities, for example household tasks, socialising or managing money, which affects someone for their whole life”. Not to be confused with someone that may have learning difficulty such as dyspraxia, dyslexia, attention deficit hyperactivity disorder (ADHD). However, they equally state that with the correct support most people with a learning disability can lead independent lives. *(What is a learning disability, Mencap 2018)* *(6)*.

Types of learning disabilities differ hugely. Someone with mild disabilities may be able to live independently with minimal support, whereas someone with severe and profound disabilities may require 24-hour care and help with performing most daily living skills.

The collective term of learning disability overshadows the person. This may lead to their health needs both physical and mental not being identified and met fully. Whilst acknowledging that the physical health impact of conditions such as Down’s syndrome is more widely known. The mental health and well-being needs of the same person may not be so widely recognised.

The Autism Act 2009 *(7)* led to the development of the *Fulfilling and Rewarding Lives - the 2010 autism strategy* *(8)*. This identified the need to improve care and access to services to support all persons living with autism. Both documents have been subsequently updated and revisited to reflect the continued desire to ensure that all needs are met.

In June 2018, National Health Service Improvement (NHSI) published its improvement standards for NHS Trusts *(9)*. The standards have been developed utilising the learning from Sir Stephen Bubb’s report *Winterbourne View Time for Change* *(2014)*, *Transforming care for people with learning disabilities next steps* *(2016)* and *Learning Disabilities Mortality Review (LeDeR) programme* *(2015)*.

The NHSI standards focus on four key areas, three of which should be adopted by all NHS Trusts (the fourth standard focuses on Trusts that provide services exclusively for people with learning disabilities autism or both).

The four standards concern:

1. Respecting and protecting rights
2. Inclusion and engagement
3. Workforce
4. Specialist LD services

Our strategy reflects these standards (1-3) and looks to embed them within the strategic aims for the organisation to complete within this three-year cycle. The strategy will be reviewed throughout to ensure the organisation is meeting its set aims.

Upon completion the Trust will review outcomes, identify learning and continue to develop all areas of its care delivery to support everyone it interacts with across all areas of Trust business.

This strategy links with the EDS2 *(5)* goals and objectives, specifically goals one and two and aligns with the *Learning Disabilities Core Skills Education and Training Framework 2016* *(10)*. This allows a benchmark to be set against the strategic aims and desired outcomes.
Strategic aims

Our strategic aims are to:

1. Deliver compassionate person-centred care and recognise the uniqueness of all living with a learning disability, autism or both
2. Develop a skilled and effective workforce able to champion compassionate person-centred care
3. Develop the ‘easy-read’ option within all Trust communications workstreams and patient care documentation.
4. Seek and action feedback from people living with a learning disability, autism or both and their carers to improve the quality of service we provide.
5. Develop internal systems that allow the patient living with a learning disability, autism or both to be placed at the centre of joint care planning whilst ensuring that that their rights are protected and respected in all aspects of Trust business.
6. Develop effective partnerships with local agencies (health, social care, third sector) to improve care and outcomes.
Objectives and measured outcomes

Strategic aim 1: Deliver person-centred care that supports the patient living with a learning disability, autism or both.

What we will do:

- Review engagement pathways and redesign the Trusts patient satisfaction surveys through a process of co-production that ensures opportunities to gather feedback from patients and carers living with learning disability, autism or both are maximised. The review will promote the user-friendly element whilst ensuring the patient voice is placed at the forefront of the review.

- Develop an educational framework that allows the sharing of recognised best practice around identifying individual needs within an urgent and emergency care and planned patient contact setting.

- Promote the NHS 6Cs (11) - Values essential to a compassionate care ethos are shared throughout all areas of the Trust’s workforce (employed and volunteers).

How success will be measured:

By the end of year one:

- A series of engagement events will be undertaken that identifies the key elements and structures required to produce service user feedback from all. The scoping exercise will look to build a clear delivery model that can be utilised across the Trust geographical footprint.

- A draft framework outlining access routes to learning and the required learning outcomes that promote the NHS 6Cs (11) as a key component will have been developed.

By the end of year two:

- Following identification, patient satisfaction surveys from people living with learning disability, autism or both will be individually reviewed by the patient satisfaction team (supported by a clinician) to identify emerging trends and themes over year two.

- Learning Disability ambassadors will have been introduced to all six of the Trust’s STP areas that fall within its geographical footprint.

By the end of year three:

- Identification and critical analysis of patient satisfaction surveys from people living with a learning disability, autism or both will have become a core part of the annual survey programme. This critical analysis will assist the Trust to determine effectiveness and identify areas for improvements.
• education/training records will demonstrate 100% of clinical/PTS staff will have
access undertaken learning disability, autism or both awareness training, and
have the necessary skills and values to care effectively outlined within the
Learning Disabilities Core Skills Education and Training Framework.

• Learning Disability ambassadors will have been introduced to all the Trust
defined operational localities.

• when surveyed at least 90% of our patients, carers and staff will feel supported.
**Strategic aim 2:** Develop a skilled and effective workforce able to champion compassionate person-centred care.

**What we will do:**

- Develop / procure a high-quality awareness and training package based on best practice and person-centred care.
- Ensure consistency of training across the whole Trust.
- Support the implementation of training.
- Monitor and evaluate the implementation of the training within EEAST.

**How success will be measured:**

By the end of year one:

- A suitable training resource for front-line clinicians and AOC staff will have been identified and procured. Early implementer localities will be identified across the Trust. All Trust directorates will formulate a delivery plan that allows staff groups access to the identified training package. Feedback will be evaluated and utilised to support year 2 roll out.

By the end of year two:

- 60% of all staff and volunteers will have undertaken learning disability/autism awareness training, and have the necessary skills and values to care effectively.

By the end of year three:

- 100% of staff and volunteers will have undertaken learning disability / autism awareness training and have the necessary skills and values to care effectively.

All clinical and psychological interventions will be based on the uniqueness and needs of all living with a learning disability, autism or both and will maintain their dignity and respect regardless of situation and presentation.
Strategic aim 3.
Develop the easy read option within all Trust communications workstreams and patient care documentation.

What we will do:

By the end of year one

- Complete a review of all Trust communications, digital communications, and patient care documentation, this review will recognise the need to remain within the requirements set arounds minimum record keeping standards for health in reference to patient care records (12).

- Identify “what good looks like” within “easy read” formats and electronic tools. This should be line with the standards outlined by the UK Association for Accessible Formats (13).

- Format a selection of key Trust documents into an easy read format to allow review and feedback to be gathered from external sources.

By end of year two:

- Using the feedback and results of study and pilot activity in year one, format an operational delivery plan to facilitate the operational roll out across all directorates of any identified changes identified in year one.

- Commence roll out within two Trust directorates identified as early implementers.

By end of year three:

- Ensure that all Trust directorates are compliant and have adopted easy read methodology into all areas of Trust business.

How success will be measured:

By the end of year one:

- Evidence that actions identified through the feedback process have been completed will be shared to support year two activity.

- External review of the Trusts early implementation directorates will identify success within year two activity.

By the end of year three:

- Easy read documents and patient care record summaries will be perceived as business as usual with in all Trust business and workstreams.
**Strategic aim 4:**
Seek and action feedback from people living with a learning disability, autism or both and their carers to improve the quality of service we provide.

**What we will do:**

By the end of year one:

- Identify groups and events that may support a “pop up” focus group that mirrors the model currently utilised within the Trusts dementia strategy 2017-20\(^{(14)}\).

By the end of year two:

- Facilitate a pop-up focus group within two of the Trust STP areas.

By the end of year three:

- Format a rolling plan that supports the patient experience team undertaking a minimum of three pop up engagement events per calendar year.

**How success will be measured:**

By the end of year three

- When surveyed at least 90% of our patients and carers living with a learning disability, autism or both will feel supported and rate our care as good/excellent.

- Clear links between EEAST and groups that support people living with a learning disability, autism or both (statutory and/or voluntary) will have been established.

- Also link to Strategic Aim 1 for patient satisfaction surveys.
**Strategic aim 5:** Develop internal systems that allow the patient living with a learning disability, autism or both to be placed at the centre of joint care planning whilst ensuring that their rights are protected and respected in all aspects of Trust business.

**What we will do:**

- Appoint a learning disability and autism lead for the Trust.
- Ensure that the Trust meets the Equality Act 2010 requirements centred on people living with learning disabilities, autism or both, and that the wider human rights of these people are respected and protected, as required by the Human Rights Act.
- Ensure that learning disability and autism friendly aspects are included in Equality Impact Assessments for new processes and procedures.
- Ensure that all parties are consulted and input into care planning for patients living with a learning disability, autism for both or their carers where the patients’ needs within their contact with the Trust would require pre-planned response or treatment.

**How success will be measured:**

By the end of year one:

- Appoint a learning disability and autism lead for the Trust.
- Undertake a scoping exercise that reviews existing Trust policies and processes to highlight any area that do not meet the current Equality Act requirements.
- Develop a framework that allows all to be included at the planning stage of care plan development.

By the end of year two:

- Where identified, any shortfall around Trust policies will be corrected.
- A guidance document will be created and piloted to support the Trust management teams to ensure that all documents created, are compliant with the needs of the Equality Act. Highlighting national guidance around respecting and protecting the rights of patients with learning disabilities, autism or both should sit at the centre of this document.
- Apply the developed framework supporting care planning to be piloted by the frequent caller team.
By the end of year three:

- All Trust documents and care plans will be compliant with legislation. They should be seen to promote a culture that supports the ethos of inclusion and respect, within all aspects of Trust business.

- Care planning framework to be considered as business as usual across all relevant Trust business.
Strategic Aim 6: Develop effective partnerships with local agencies (health, social care, third sector) to improve care and outcomes.

What we will do:

- We will review existing care pathways to improve any identified deficits to streamline care and avoid taking people to Emergency Departments when this is not necessary.

- We will develop digital pathways that facilitate accessing appropriate professionals with expertise in learning disabilities that can support patients, carers, relatives and EEAST staff to meet the needs of the all accessing healthcare through the 999 system.

- We will develop partnerships with learning disability and autism health and/or social care providers.

How success will be measured:

By the end of year one

- All relative care pathways will have been reviewed and updated to reflect the needs of people living with a learning disability, autism or both.

- A review of existing links with the relative health/social/care providers will have been completed.

- A scoping exercise will have been completed that identifies the appropriate professional group to support the development of digital pathways for EEAST staff working within an Ambulance Operations Centre (AOC).

By the end of year two:

- Contacts will have been made with key groups in each EEAST localities.

- A local pilot will have been undertaken that supports an access to specialist HCP support through a digital pathway to support the clinical function within EEAST AOCs.

By the end of year three:

- Meetings with key groups will be attended and incorporated in to Trust business as usual.

- Pathways allowing access to specialist HCP support through a digital medium supporting the clinical function within EEAST AOCs will be delivered as Trust business as usual.
# Monitoring and assurance of the Learning Disability Strategy and action plans

Progress will be monitored by the Patient Experience team (Surveys) in conjunction with the named Learning Disabilities Lead and reporting to the Clinical Quality and Safety Group.

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The clinical lead for Mental Health, Learning Disability and Dementia will advise and support the nominated leads, as necessary.

The lead of each work stream will report progress and exceptions to the Patient Experience team (Surveys) and named Learning Disabilities lead when requested and as a minimum annually.

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EEAST Learning Disability Strategy – Version 6.1

#WeAreEEAST
References


(11) NHS England » The 6Cs: https://www.england.nhs.uk/leadingchange/about/the-6cs/

(12) Professional guidance on the structure and content of ambulance records: https://www.rcplondon.ac.uk/guidelines-policy/professional-guidance-structure-and-content-ambulance-records
(13) UK Association for Accessible Formats
https://www.ukaaf.org/minimum_standards/

(14) EEASt Dementia Strategy:

(15) Equality Act 2010: