

# The learning disability improvement standards for NHS trusts

June 2018

As part of developing these improvement standards, NHS Improvement identified some services that provide care to people with learning disabilities, autism or both, and others that provide care only to those with learning disabilities. We use the term 'people with learning disabilities, autism or both' in these standards, but advise discretionary interpretation of the term to compliment the particular service against which the standards are being applied.

We support providers to give patients safe, high quality, compassionate care within local health systems that are financially sustainable.

# Contents

Introduction .....	2
Standard 1: Respecting and protecting rights .....	6
Standard 2: Inclusion and engagement .....	9
Standard 3: Workforce .....	12
Standard 4: Specialist learning disability services .....	15

# Introduction

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. They should receive treatment, care and support that are safe and personalised; and have the same access to services and outcomes as their non-disabled peers.

But we know some people with learning disabilities, autism or both encounter difficulties when accessing NHS services and can have much poorer experiences than the general population. Several inquiries and investigations have found that some NHS trusts and foundation trusts<sup>1</sup> are failing to adequately respect and protect people's rights, with devastating consequences for them and their families. Also, skills deficits in the NHS workforce mean people's needs are sometimes misunderstood or responded to inappropriately. As a result of these failings, people with learning disabilities, autism or both are at risk of preventable, premature death and a grossly impoverished quality of life.<sup>2</sup>

With system partners we have developed four standards that trusts need to meet; doing so identifies them as delivering high quality services for people with learning disabilities, autism or both. These standards are supplemented by improvement measures or actions that trusts are expected to take to make sure they meet the standards and deliver the outcomes that people with learning disabilities, autism or both and their families expect and deserve.

NHS Improvement will look at performance against these standards to target support at those trusts that need to improve.

## A rights-based approach

We all have human rights; and people with learning disabilities, autism or both have the same rights as everyone else. The main law protecting human rights in the UK is the Human Rights Act, which places a clear legal duty on public officials to respect the 16 rights it outlines. Several of these rights are particularly relevant to

<sup>1</sup> Referred to collectively as trusts in these standards.

<sup>2</sup> National Quality Board (2017) [National guidance on learning from deaths: A framework for NHS trusts and NHS foundation trusts on identifying, reporting, investigating and learning from deaths in care.](#)

the design and delivery of health services: the right to life; the right to be free from inhuman/degrading treatment; the right to liberty; the right to respect for private and family life; and the right to be free from discrimination.

Services for people with learning disabilities, autism or both should be provided as close as possible to their homes and communities, and must be of the same quality as those delivered to other members of society. These services need to include effective public health services as well as the specialist services for a disability (including early identification and intervention services). Practitioners must respect people's autonomy by ensuring they seek free and informed consent to care and treatment, and that people are helped to understand their rights.

The Human Rights Act places a duty on officials both to 'respect' human rights and to take action to ensure people's rights are 'protected'. This includes protecting people from known risks to their rights (such as risk of abuse or loss of life), preventing discrimination, and promoting inclusion and participation.

To enable people with learning disabilities, autism or both to have the same human rights as the general population, their specific requirements need to be reflected in all NHS trust policies and procedures. These standards are rooted in a human rights-based approach to meeting people's needs.

## Standards for improvement

Unwarranted variation in care and the poorer outcomes sometimes experienced by people with learning disabilities, autism or both mean trusts need to sustainably improve many of their services. These standards provide a benchmark against which all trusts, be they universal or specialist healthcare providers, can measure their performance in delivering services to people with learning disabilities, autism or both, so driving quality improvement.

The standards reflect the strategic objectives and priorities described in national policies and programmes, in particular those arising from [Transforming care for people with learning disabilities – next steps](#) and the [Learning Disabilities Mortality Review \(LeDeR\) programme](#).

They also reflect the work of other arm's length bodies, in particular that of NHS England, the Care Quality Commission (CQC) and Health Education England (HEE). CQC has embedded a human rights-based approach in its regulatory

framework since 2014;<sup>3</sup> this has been a powerful driver for change in trusts. The standards and improvement measures align with the eight key lines of enquiry that are central to the developmental reviews of leadership and governance using the well-led framework<sup>4</sup> that trusts are charged with undertaking. This ensures these reviews specifically consider service delivery to people with learning disabilities, autism or both.

The four standards concern:

- 1. respecting and protecting rights**
- 2. inclusion and engagement**
- 3. workforce**
- 4. specialist learning disability services.**

The first three standards should be met by all trusts; the fourth is specifically for trusts that provide services commissioned exclusively for people with learning disabilities, autism or both.

Compliance with these standards requires trusts to assure themselves that they have the necessary structures and processes, workforce and skills to deliver the outcomes that people with learning disabilities, autism or both, their families and carers expect and deserve. It also demonstrates a commitment to sustainable quality improvement in developing services and pathways for people with learning disabilities, autism or both.

Trusts are expected to publish their performance against these standards in their annual quality accounts: to demonstrate to the population they serve how they measure quality of services and whether quality is improving. Each standard has its own improvement measures.

<sup>3</sup> Care Quality Commission (2014) [Human rights approach for our regulation of health and social services](#).

<sup>4</sup> NHS Improvement (2017) [Developmental reviews of leadership and governance using the well-led framework](#).

NHS Improvement will use performance against the individual performance measures to target tailored support and intervention at those trusts where improvement is most needed. Our first aim will be to expedite progress against the high-level ambitions that are central to national policy.

Over the next 12 months we will provide further guidance and tools to help trusts quantify and demonstrate their performance against the improvement measures.

# Standard 1: Respecting and protecting rights

All trusts must ensure that they meet their Equality Act Duties to people 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.

## The improvement measures: What trusts need to be doing to meet the standard

Improvement measure	What this means in practice
Trusts must demonstrate they have made reasonable adjustments to care pathways to ensure people with learning disabilities, autism or both can access highly personalised care and achieve equality of outcomes.	This typically includes things like using modified communication, flexible appointment systems and modified triage assessments, and ensuring due regard to the content of hospital passports.
Trusts must have mechanisms to identify and flag patients with learning disabilities, autism or both from the point of admission through to discharge; and where appropriate, share this information as people move through departments and between services.	This might be done using electronic flags in patient administration systems and ensuring the necessary reasonable adjustments are recorded in a person's summary care record.
Trusts must have processes to investigate the death of a person with learning disabilities, autism or both while using their services, and to learn lessons from the findings of these investigations.	Both local investigations and full engagement with the national LeDeR programme. Also, acting to address findings of investigations.



Trusts must demonstrate that they vigilantly monitor any restrictions or deprivations of liberty associated with the delivery of care and treatment to people with learning disabilities, autism or both.	Trusts have arrangements to ensure any restrictions and deprivations of liberty are correctly and lawfully authorised, with checks that these are always necessary and proportionate.  Trusts are transparent about what they do and why, and are open to challenge.
Trusts must have measures to promote anti-discriminatory practice in relation to people with learning disabilities, autism or both.	Trusts 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.  Trusts compare outcomes and experiences of people with learning disabilities, autism or both with those of non-disabled peers.

## Resources

Care Quality Commission (2016) [\*Learning, candour and accountability: A review of the way NHS trusts review and investigate the deaths of patients in England.\*](#)

CIPOLD (Confidential Inquiry into premature deaths of people with learning disabilities) (2013), Norah Fry Research Centre, University of Bristol.  
<http://www.bris.ac.uk/cipold/>

Department of Health (2008) [\*Healthcare for all: Report of the independent inquiry into access to healthcare for people with learning disabilities.\*](#)

Mencap (2007) [\*Death by indifference.\*](#)

National Quality Board (2017) [\*National guidance on learning from deaths.\*](#)

NHS England (2016) [\*Accessible information standard.\*](#)

University of Bristol School for Policy Studies [\*The learning disabilities mortality review \(LeDeR\) programme – resources and information.\*](#)

## The respecting and protecting rights standard in action

A 52-year-old man with a moderate learning disability and autism visited his GP because he had a significantly enlarged testicle. The GP was unable to fully examine him, so support staff contacted the hospital liaison service at James Paget University Hospitals NHS Foundation Trust for advice.

An urgent planning meeting was arranged. As the man lacked capacity to consent or dissent, the liaison nurse arranged a best interest planning meeting. A highly personalised approach was agreed, with reasonable adjustments to usual pathways of care.

Consultant doctors visited the man at home so he did not need to attend outpatient clinics. He was subsequently anaesthetised in his home, with his favourite carer beside him and while holding his prized Argos catalogue. The man was then quickly and safely transferred by private ambulance to an operating theatre at a local hospital, where he was examined and immediately treated. He continued to be monitored and supported by the anaesthetist during his transport back home, and anaesthesia was only withdrawn once home.

# Standard 2: Inclusion and engagement

Every trust must ensure all people with learning disabilities, autism or both and their families and carers are empowered to be partners in the care they receive.

## The improvement measures: what trusts need to be doing to meet this standard

Improvement measure	What this means in practice
Trusts must demonstrate processes that ensure they work and engage with people receiving care, their families and carers, as set out in the NHS Constitution.	<p>Trusts involve people, families and carers in all aspects of planning and evaluating care and treatment, and use their feedback and experiences to improve services.</p> <p>Trusts tell people if their care has raised safety concerns and what will be done to prevent recurrences.</p>
Trusts must demonstrate that their services are 'values-led'; for example, in service design/improvement, handling of complaints, investigations, training and development, and recruitment.	<p>Trusts make clear the attitudes, behaviours and communication they expect from their staff.</p> <p>Trusts support people whose complaints and concerns are being looked into.</p> <p>Trusts involve people with learning disabilities in staff recruitment.</p>
Trusts must demonstrate that they co-design relevant services with people with learning disabilities, autism or both and their families and carers.	<p>This includes involvement of people, families and carers in reviewing services/pathways that affect them and planning improvements.</p>

	Some organisations ensure that people with learning disabilities, autism or both are fully involved in strategic decision-making and designing approaches to continuous learning.
Trusts must demonstrate that they learn from complaints, investigations and mortality reviews, and that they engage with and involve people, families and carers throughout these processes.	This might include, for example, adopting NHS England's initiative ' <a href="#">Ask Listen Do</a> '.  In line with the LeDeR reviews, trusts should invite the input of people and families affected, to maximise learning from untoward events.
Trusts must be able to demonstrate they empower people with learning disabilities, autism or both and their families and carers to exercise their rights.	This might include commissioning people with learning disabilities, autism or both to independently review services, and paying them for any work they do.  Trusts actively inform people of their rights, in a manner that is meaningful to them.

## Resources

National Quality Board (2017) [National guidance on learning from deaths](#).

[NHS Constitution for England](#) (2015).

NHS England (2013) [Transforming participation in health and care](#).

NHS England (2014) [Transforming care the next steps](#).

NHS England (2016) *Always events*.

<https://www.england.nhs.uk/ourwork/pe/always-events/>

<https://www.england.nhs.uk/learningdisabilities/projects/>

NHS England (2017) [Ask Listen Do](#).

Quality Checks <https://www.changingourlives.org/quality-checking>

Skills for Health, Skills for Care and Health Education (2016) [Learning disabilities core skills education and training framework](#).

The British Institute of Human Rights (2017) [Learning disability, autism and human rights](#).

## The inclusion and engagement standard in action

Over an eight-year period Changing Our Lives, a rights-based organisation, worked with Sandwell and West Birmingham Hospitals NHS Trust to check the quality of care for people with learning disabilities, autism or both using its acute hospital services.

The first quality check in 2009 identified the need for a learning disability liaison nurse and this post was created the following year. Subsequent quality checks measured this post's impact on patient experience, family carer experience and ways of working in a range of hospital teams.

Checks were led by trained and paid experts by experience with learning disabilities, independently supported by Changing Our Lives.

# Standard 3: Workforce

All trusts must 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 improvement measures: what trusts need to be doing to meet this standard

Improvement measure	What this means in practice
<p>Based on analysis of the needs of the local population, trusts must ensure staff have the specialist knowledge and skills to meet the unique needs of people with learning disabilities, autism or both who access and use their services, as well as those who support them.</p>	<p>Trusts understand patterns of local need among people with learning disabilities, autism or both, and use this knowledge to determine what skills are required and then recruit the right staff in the right numbers.</p>
<p>Staff must be trained and then routinely updated in how to deliver care to people with learning disabilities, autism or both who use their services, in a way that takes account of their rights, unique needs and health vulnerabilities; adjustments to how services are delivered are tailored to each person's individual needs.</p>	<p>This is likely to include ensuring staff have been trained in: learning disabilities and autism awareness; health issues associated with learning disabilities; supporting people with challenging needs; safeguarding; human rights and mental capacity and best interests.</p>
<p>Trusts must 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>	<p>This might include supporting new, emerging roles such as advanced practitioners, apprenticeships, consultant allied health professionals and nurses, clinical academic roles and non-medical prescribers, and</p>

	employing experts by experience/peer workers.
Trusts must demonstrate clinical and practice leadership and consideration of the needs of people with learning disabilities, autism or both, within local strategies to ensure safe and sustainable staffing.	This includes trusts having a designated lead for learning disabilities, as well as providing induction, mentorship, supervision and appraisal that explore how people with learning disabilities, autism or both are being supported.

## Resources

Health Education England [Inspirational leader](#)

Practical information and resources for developing staff at all levels.

Health Education England [Workforce capability](#).

Information and resources.

National Quality Board (2013) [How to ensure the right people, with the right skills, are in the right place at the right time: A guide to nursing, midwifery and care staffing capacity and capability](#).

NHS England (2015) [Safeguarding vulnerable people in the NHS – Accountability and assurance framework](#).

NHS Improvement (2018) [Safe staffing in learning disability services](#).

A resource to help standardise staffing decisions for learning disability services in community and inpatient settings.

The British Institute of Human Rights (2016) [Learning disability and human rights: A practitioner's guide](#).

## The workforce standard in action

Norfolk and Suffolk NHS Foundation Trust redesigned its services to ensure people with learning disabilities, autism or both can receive mental health support from mainstream mental health services. Many staff working in its mental health services had been identified as not possessing the required skills to meet the needs of people with learning disabilities, autism or both.

Areas for improvement were identified using the [Green Light toolkit](#). A registered learning disability nurse was seconded to lead a project to improve the access to and inclusion within the mainstream mental health services for people with learning disabilities, autism or both. The aim of the project was to drive up standards and effect positive culture change by raising awareness of learning disability, autism or both in mainstream mental health services. In a further Green Light audit in 2018 the trust had improved on all 27 standards in the Green Light toolkit.

The trust now has 187 'Green Light champions' among trust staff, service users and colleagues in partner organisations such as social care. Their role is to improve the experience of mainstream mental health services for people with learning disabilities, autism or both, share ideas for change and promote best practice.



# Standard 4: Specialist learning disability services

Trusts that provide specialist learning disabilities services commissioned solely for the use of people with learning disabilities, autism or both must fulfil the objectives of national policy and strategy.

## The improvement measures: what trusts need to be doing to meet this standard

Improvement measure	What this means in practice
Trusts must have plans for the development of community-based intensive support, including treatment and support for people accessing mental health services and the criminal justice system.	This includes developing new specialist community services, or upskilling existing teams and expanding their remit. Trusts may also agree collaborative and co-ordinated joint working arrangements with local partners.
Trusts use the care and treatment review (CTR) and care and education treatment review (CETR) to ensure a stringent assessment is made if admission is anticipated or requested, and that discharge arrangements ensure no individual stays longer than necessary.	Trusts fully comply with the national standards for CTRs and CETR; providing the treatments that are needed and having an assertive approach to discharge planning.
Trusts have processes to regularly review the medications prescribed to people with learning disabilities, autism or both. Specifically, prescribing of all	Specialist practitioners contribute to medication reviews. A person's past experience of adverse reactions and their preferences are considered,

<p>psychotropic medication should be considered in line with NHS England's programme stopping over medication programme <a href="#">STOMP</a>.</p>	<p>including psychosocial alternatives to medication, and people have the right support when their medication is reduced.</p>
<p>Trusts providing inpatient services have clinical pathways that adhere to evidence-based assessment and treatment, time-limited interventions and measurable discharge processes to ensure inpatient episodes are as short as possible.</p>	<p>This means ensuring that there are clear discharge pathways, which are initiated on admission and shared with people and their families. It also means National Institute for Health and Care Excellence (NICE) guidelines are appropriately applied to people with learning disabilities, autism or both.</p>
<p>Trusts 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. They can demonstrate that alternative approaches are being deployed.</p>	<p>This includes having a clearly designated executive-level lead for restrictive intervention reduction and an overarching restrictive intervention reduction policy.</p> <p>Data on restrictive interventions is collected, analysed and made publicly available.</p>

## Resources

NHS England (2015) [Service model for commissioners of health and social care services](#).

NHS England (2015) [Care and treatment review: policy and guidance](#).

NHS England (2015/16) Building the right support; one year on, two years ahead.  
<https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>  
<https://www.england.nhs.uk/learningdisabilities/natplan/building-the-right-support/>

NHS England (2016) [Stopping over medication of people with a learning disability, autism or both \(STOMP\)](#).

NHS England (2017) [Care and treatment review workbooks](#).

Social Care Institute for Excellence (SCIE) (2015) [Restraint: a human rights issue](#).

## The specialist services standard in action

Oxford Health NHS Foundation Trust specialist learning disability service surveyed people admitted to inpatient beds out of area and their families about their experiences, to inform what it needed to offer locally and how. As a result, the service has invested in a well-resourced, all-age intensive support team with much greater capacity and capability to prevent admissions.

By focusing on human factors and working with people who have been admitted to services and their families, the service was able to develop faster, person-centred solutions. Also, by being involved in NHS Improvement's collaborative on discharge planning, the trust was able to focus on supporting people's discharge from the point of admission.

Working in partnership with a neighbouring trust, the service is taking a more individualised approach to deploying support. This process is underpinned by a quality assurance process that helps to ensure any inpatient episode is kept to a minimum and intensive community support is readily available.

Contact us:

**NHS Improvement**

Wellington House  
133-155 Waterloo Road  
London  
SE1 8UG

**0300 123 2257**

**enquiries@improvement.nhs.uk**  
**improvement.nhs.uk**

 **@NHSImprovement**

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