



Benchmarking Network



# Performance against the learning disability improvement standards

Findings from the benchmarking exercise

July 2019

NHS England and NHS Improvement



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# 1. Introduction

Over a million people in England have a learning disability and we know they often experience poorer access to healthcare than the general population. The [NHS Long Term Plan](#) (January 2019) commits the NHS to ensuring all people with a learning disability, autism or both can live happier, healthier, longer lives.

In June 2018, NHS Improvement launched the national [learning disability improvement standards for NHS trusts](#). These were designed with people with a learning disability, carers, family members and healthcare professionals to drive rapid improvement of patient experience and equity of care.

The four standards, the first three of which apply to all NHS trusts, cover:

- respecting and protecting rights
- inclusion and engagement
- workforce
- specialist learning disabilities services.

A trust's compliance with these standards demonstrates it has the right structures, processes, workforce and skills to deliver the outcomes that people with learning disabilities, autism or both, their families and carers expect and deserve, as well as commitment to sustainable quality improvement in the services and pathways for this group.

To deliver these standards and achieve the vision of the Long-Term Plan, NHS trusts need to optimise access to healthcare for people with learning disabilities, autism or both: this requires organisational development and collaboration with other providers.

This report documents our findings from the first collection of data on trust performance against the four standards. It provides a holistic view from the perspectives of people with a learning disability, their carers and families, staff and organisations, and insight into the specific quality of care indicators, activity data and workforce indicators.

This data gives the baseline position against which progress can now be measured, allows NHS trusts to compare their performance with that of their peers and helps us develop strategies for the successful implementation of the standards.

## 2. The learning disabilities improvement standards benchmarking project

2018/19 was the first year of the learning disabilities improvement standards project – a pilot year in which we gathered baseline information from providers on their compliance with the standards, together with the views of staff and patients.

Using NHS Improvement's learning disability toolkit, NHS Benchmarking Network and NHS Improvement together developed an organisational-level data collection, a staff survey and a service user survey, with the three triangulated in this pilot benchmarking exercise. The toolkit is based on the four learning disability improvement standards. The draft questionnaires were reviewed by NHS Benchmarking Network member organisations (mental health reference group), patient groups, people with learning disabilities and carers, and other professionals identified by NHS Improvement. The service user and staff questionnaires were designed with information governance and General Data Protection Regulation (GDPR) compliance.

We surveyed providers, staff and service users between 17 September and 31 December 2018, running this exercise alongside NHS Benchmarking Network's core learning disabilities project that has collected data on NHS-provided specialist learning disability services for the last four years.

### Data collection

Trusts were given three months to collect the required data (for 2017/18). For the organisational-level survey, trusts were advised to get a group of key individuals collectively to respond on its behalf, to reduce the risk of bias. Data collection was online via the NHS Benchmarking Network portal. We provided trusts with an Excel spreadsheet version of the dataset metrics to make data collection as easy as possible.

We also provided trusts with information governance and GDPR-compliant guidance on identifying patients and staff to invite to complete the surveys. They

were asked to identify 20 members of staff and up to 80 service users.

Both the service user and staff surveys were available online and participants were given a unique access code to the online data collection pages to allow them to respond anonymously. Service users were initially sent a letter asking for their explicit consent to participate and offered telephone advice and support to complete the survey from Pathways Associates, a learning disabilities support organisation.

## Data validation, analysis and reporting

The project team validated and analysed the data from the three collections. Where there appeared to be errors, we contacted organisations to discuss the quality of their data. Where required, we accepted and included revisions in our analysis.

## Participation

A total of 213 organisations from across England registered for the project. They divide by organisation type as follows:

Organisation type	Number
Specialist LD service provider*	63
Acute	129
Community	8
Mental health with no specialist LD service	6
Ambulance	7

\* Organisations were asked to identify if they provided a specialist LD service and if they were registering as a specialist provider.

Of these organisations:

- **191** completed the organisational-level data collection
- **189** surveyed their staff, returning **2,168** completed surveys
- **119** surveyed their service users, returning **635** completed surveys. The target number of participants for this survey was 580.

**Acknowledgement:** We thank all the organisations that participated in this pilot year of the benchmarking project. Thank you also to Pathways Associates.

# 3. Findings

The improvement measures supporting delivery of the standards indicate how well an organisation is doing, and this data collection provides the baseline for the quality of care English NHS organisations are delivering to people with a learning disability, autism or both. We will measure progress in implementing the learning disabilities improvement standards against this baseline.

Many trusts are performing well and can demonstrate commitment to service improvement. However, variation is evident across England, and even the best performing organisations have identified areas where compliance with the standards should be improved and made more systematic, particularly the ability to reliably identify people with a learning disability and having the capacity to ensure effective system-wide liaison and co-ordination. Doing so will better position providers to deliver the vision of the NHS Long Term Plan for people with learning disabilities, autism or both.

In this section we summarise the findings; more detail can be found in the appendices. All data is for the financial year 2017/18.

For the purpose of reporting, where the data from universal trusts and specialist trusts present similar findings, we have aggregated their performance percentages, but where findings are specific to one or the other type of trust we make this clear. As the standards are developed as part of the NHS Long Term Plan, we anticipate findings from universal and specialist provider organisations will be presented separately.

## 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.

flag people with learning disabilities, autism or both as they access and progress through their services; make reasonable adjustments across their pathways of care; promote anti-discriminatory practice; effectively monitor any restrictions on people's freedom; and have robust processes to learn lessons and make improvements.

Findings are summarised in Table 1 below and given in full in [Appendix 1](#).

Those trusts performing well against Standard 1 identify and

**Table 1: Summary of performance against Standard 1**

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
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.	<p><b>83%</b> of acute hospital staff said they record and share information about the reasonable adjustments people need.</p> <p><b>54%</b> of people with learning disabilities who had used an acute hospital service saw a learning disability liaison nurse. Only <b>6%</b> of this group reported unhappiness with this support.</p>	

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
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.	<p><b>79%</b> of acute hospital trusts have electronic systems to flag up people with a learning disability.</p> <p><b>99%</b> of trusts agreed that anyone in hospital should have access to advocacy services.</p>	<p><b>77%</b> of acute hospital trusts are unable to recognise if someone on a waiting list has a learning disability.</p>
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.	<p><b>98%</b> of trusts have implemented improvement plans to reduce preventable deaths.</p> <p><b>71%</b> of trusts that have LeDeR reviewers undertake a minimum of two to three reviews a year.</p>	
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.	<p><b>82%</b> and <b>93%</b> of specialist learning disability providers and acute hospital trusts respectively have a policy for restrictions and deprivations of liberty, and <b>75%</b> and <b>83%</b> respectively conduct audits of restrictions.</p>	
Trusts must have measures to promote anti-discriminatory practice in relation to people with learning disabilities, autism or both.	<p><b>94%</b> of people with learning disabilities said they were treated with respect when using their trust's services.</p>	<p>Only <b>45%</b> of specialist learning disability services and <b>37%</b> of acute hospital trusts maintain contact with people with learning</p>

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
		<p>disabilities who are waiting to be seen and offer flexible appointments.</p> <p><b>75%</b> of acute hospital trusts do not specifically monitor and review the waiting times experienced by people with learning disabilities.</p>

## 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.

A good service is provided by a values-led organisation that engages people with learning disabilities, autism or both as active partners in their own care. Those performing well

against Standard 2 empower and support people to exercise their rights and be fully engaged in reviewing and developing services.

They ensure that people with learning disabilities and families are fully involved as partners, both when looking to improve and in investigations when something goes wrong.

Findings are summarised in Table 2 below and given in full in [Appendix 2](#).

**Table 2: Summary of performance against Standard 2**

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
<p>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>	<p><b>89%</b> of acute hospital trusts have triage services that prioritise people with learning disabilities who are distressed.</p> <p><b>86%</b> of acute hospital trusts produce accessible information about the services they provide.</p> <p><b>80%</b> of specialist learning disability services produce accessible appointment letters.</p> <p><b>76%</b> of acute hospital trusts provide discounted/free parking for families and carers of those with learning disabilities.</p>	<p>Only <b>26%</b> of trusts have dedicated positions on their council of governors or board subcommittees for people with learning disabilities.</p> <p><b>55%</b> of acute hospital trusts do not provide accessible appointment letters.</p> <p><b>13%</b> of people with learning disabilities said they had made a formal complaint; <b>31%</b> said they had wanted to make a complaint or raise a concern about their care.</p> <p><b>33%</b> of people with learning disabilities were not shown accessible information about how to make a complaint.</p>
<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>	<p><b>67%</b> of trusts involve people with learning disabilities in checking the quality of services.</p> <p><b>75%</b> of trusts employ people with learning disabilities. On average, amongst those trusts who provided data, there were <b>6</b> whole time equivalent</p>	

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
	(WTE) employees who had a learning disability.	
Trusts must demonstrate that they co-design relevant services with people with learning disabilities, autism or both and their families and carers.	<b>98%</b> of acute hospital trusts have on-site facilities to accommodate family carers overnight.	<b>57%</b> of acute hospital trusts and <b>64%</b> of specialist learning disability services do not have 'changing places' toilets on site.
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.		<b>28%</b> of staff do not feel that when something goes wrong, their trust works with people with learning disabilities and families to put things right and stop it happening again.
Trusts must be able to demonstrate they empower people with learning disabilities, autism or both and their families and carers to exercise their rights.	<b>57%</b> of staff felt people's rights are always explained to them; and <b>68%</b> of people with learning disabilities said staff had spoken to them about their rights.	<b>27%</b> of people with learning disabilities said that staff did not check if they had an advocate.

## 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.

Maintaining workforce is an important challenge facing the NHS. The improvement measures highlight the benchmark

required to ensure effective delivery of a range of policy ambitions. The survey positively identified organisations that have workforce plans which are underpinned effective clinical and practice leadership. These plans included measures to address cross system workforce pressures and highlighted where staff are well trained around the needs of people with learning disabilities and autistic people.

Findings are summarised in Table 3 below and given in full in [Appendix 3](#).

**Table 3: Summary of performance against Standard 3**

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
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><b>92%</b> of specialist learning disability services and <b>95%</b> of acute hospital trusts have a board-level lead for learning disabilities.</p> <p><b>77%</b> of staff in acute hospital trusts said they knew how to access specialist advice around the needs of people with learning disabilities.</p>	

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
<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><b>79%</b> of trusts train staff in learning disability awareness; <b>53%</b> of staff surveyed confirmed this to be the case.</p>	<p>Only <b>21%</b> of trusts involve people with learning disabilities in the delivery of induction training.</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><b>80%</b> of specialist learning disability services have plans to introduce new roles such as advanced practitioners and nursing associates.</p>	<p><b>38%</b> of staff feel their trust does not have enough staff with the right skills to support people with learning disabilities. The workforce plans for <b>29%</b> of specialist learning disabilities services do not include data on workforce pressures related to recruitment and retention.</p>
<p>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.</p>	<p><b>55%</b> of acute hospital trusts employ acute liaison nurses. The remainder have an arrangement for an equivalent service with another NHS trust.</p>	<p><b>37%</b> of trusts do not have an identified care co-ordinator for people with learning disabilities who have multiple long-term conditions.</p>

## Standard 4: Specialist 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.

Organisations effectively meeting this standard are delivering or developing specialist community support services to reduce the likelihood of people being admitted to specialist

learning disability hospitals. They are using care and treatment reviews to avoid admissions wherever possible and making sure people have plans in place for a timely discharge. These organisations have clinical pathways aligned to an evidence base and convene regular reviews to ensure people do not take medications they do not need. These services also have active programmes to reduce the use of restrictive practices.

Findings are summarised in Table 4 below and given in full in [Appendix 4](#).

**Table 4: Summary of performance against Standard 4**

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
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.	<p><b>98%</b> of trusts provide positive behavioural support.</p> <p>At <b>94%</b> of trusts community practitioners continue to be involved if a person is admitted to hospital; <b>79%</b> of staff surveyed said this was the case.</p> <p><b>73%</b> of trusts have clear pathways for intensive support services.</p>	<p><b>44%</b> of trusts do not provide specialist community forensic services.</p> <p><b>41%</b> of intensive community support services do not operate seven days a week.</p> <p><b>26%</b> of intensive support services do not provide crisis support.</p>

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
<p>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.</p>	<p><b>90%</b> of intensive community support teams co-ordinate transitions out of inpatient services.</p> <p><b>76%</b> of specialist learning disability inpatient services have governance systems to monitor target and actual discharge dates.</p>	
<p>Trusts 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 stopping over medication programme (STOMP).</p>		<p>Only <b>62%</b> of services have a clear policy to safeguard people from inappropriate use of psychotropic medication.</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><b>75%</b> of trusts have processes to check their care pathways are aligned to national guidance and evidence.</p>	

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
<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><b>89%</b> of staff in specialist learning disability services said they have received training in reducing the need for restrictive interventions.</p>	

## 4. Next steps

This report summarises the findings from the pilot year of the NHS Improvement learning disability improvement standards benchmarking project. All participating trusts will receive a bespoke report giving an overview of their compliance with the standards, with their individual positions highlighted against each of the standards. Participating organisations have access to their own data through the NHS Benchmarking Network [website](#).

NHS Improvement's learning disabilities team will continue to work with colleagues in organisations across England to share best practice and shape service improvement projects at a local level. The information in this report can be used as the basis for service improvement, and we will collate and analyse metrics annually to allow trusts to monitor their improvement and identify areas of strength and weakness.

If you would like to be involved in shaping and developing the data collection metrics for next year's project, please contact [jessica.walsh1@nhs.net](mailto:jessica.walsh1@nhs.net).

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