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Performance against the learning disability improvement standards

Findings from the year 3 national benchmarking exercise 2020

January 2022

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1. Introduction

The over 1.2 million people in England with a learning disability and 200,000 autistic people should be able to expect high quality, personalised and safe care when they use the NHS. Unfortunately, they sometimes experience poorer access to healthcare than the general population. The NHS Long Term Plan commits the NHS to ensuring all people with a learning disability and autistic people 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, autistic people, carers, family members and healthcare professionals, to drive rapid improvement in patient experience and equity of care.

The four improvement standards against which trust performance is measured cover:

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

The first three 'universal standards' apply to all NHS trusts, and the fourth 'specialist standard' applies specifically to trusts that provide services commissioned exclusively for people with a learning disability or autistic people.

A trust's compliance with these standards demonstrates it has the right structures, processes, workforce and skills to deliver the outcomes that people with a learning disability, autistic people, their families and carers expect and deserve, as well as commitment to sustainable quality improvement in the services and pathways for this group. We expect trusts to publish details of their performance against these improvement standards in their annual quality accounts, and to demonstrate a sustainable improvement in their quality of services. Each of the four standards has a set of improvement measures that trusts are expected to adopt.

This report documents findings from the third national collection of data on NHS trusts' performance against the four improvement standards, for 2020. The three-pronged

approach of organisational, staff and patient information collection provides a holistic view of the workforce, activity, service models and quality of services provided to people with a learning disability and autistic people.

All participating trusts receive a bespoke report giving an overview of their compliance with the standards and have access to their data through the NHS Benchmarking Network (NHSBN) secure online portal.

We thank everyone who provided data for this collection and helped validate their positions in the draft findings during this particularly challenging year for the NHS.

If you have any questions about this report or would like to be involved in shaping the data collection, please contact the NHS Benchmarking Network support team at nhsbn.nhsildsupport@nhs.net.

2. The learning disabilities improvement standards project

Each year we gather information from providers on their compliance with the standards and survey people with a learning disability and autistic people and some of the staff who have supported them. This exercise runs alongside NHSBN's core learning disabilities project that has collected data on NHS specialist learning disability services for the past six years.

The data we collected includes 2019/20 annual trust activity data, as well as status reports on systems and processes; and staff and patient perspectives were surveyed during the data collection period running from 23 November 2020 to 31 March 2021. This year we extended the data collection window because of the impact of COVID-19.

Since the first data collection, we have enhanced several data items and aspects of the survey methodology to reflect the feedback from people with a learning disability, autistic people, families, healthcare practitioners and managers. Notably, from the second collection onwards we introduced a section concerning the use of restrictive

interventions, to be completed by trusts providing specialist services specifically for people with a learning disability and autistic people, in response to ongoing national concerns regarding such practices.

Data collection

We gave trusts five months to collect and submit the required activity data (for 2019/20). They could assign multiple staff members to input data through NHSBN's data collection portal, and NHSBN provided them with an Excel spreadsheet of the required metrics, to make data collection as easy as possible.

NHSBN also provided trusts with information governance and GDPR compliance guidance on identifying and inviting service users with a learning disability or who are autistic, and staff to complete their respective surveys. They were asked to identify up to 50 members of staff who had supported patients with a learning disability or autistic people and up to 100 service users.

Staff surveys were completed online, with each trust given a unique URL link that allowed 50 staff members to submit answers anonymously. Service user information was collected through a multiple choice paper survey returned anonymously to a thirdparty provider (Restore Digital) in a freepost envelope.

Data validation and analysis

NHSBN analysed and validated the data collected, providing trusts with a draft interactive toolkit for validation purposes. It flagged what appeared to be errors to trusts and gave them the opportunity to review their submission and resubmit their data.

Participation

Organisation type	Number
Specialist learning disabilities service provider	50
Universal service provider	151
Acute (hospital) trust	131
Community health trust	11
Mental health trust	5
Ambulance trust	1
Community interest company	3

A total of 201 organisations from across England participated in the collection, of which 50 provided specialist learning disability or autism services and 151 universal services that are for everyone, including people with a learning disability and autistic people, e.g., an outpatient department or A&E. Of these:

- 178 completed the organisational-level data collection.
- 172 surveyed their staff, returning 4,548 completed surveys.
- 152 surveyed their service users, returning 2,884 completed surveys.

3. Key findings

In considering the data presented in this report, it is important to recognise the potential impact of the COVID-19 pandemic. While organisational activity data is for the largely pre-pandemic year 2019/20, NHS trusts made some anticipatory changes to normal service before the end of March 2020. Staff and service user surveys were completed in late 2020 through to early 2021 and are therefore likely to reflect experiences of service delivery during the pandemic and its associated restrictions. Corporate 'end of year' position statements for 2019/20 were submitted by responsible trust leads during the same data collection window and are also similarly likely to have been influenced by pandemic pressures.

The continued use of a three-pronged approach of organisational level, staff level and service user level data collection allows an analysis of how trusts are performing against the national learning disability improvement standards. As this is the third national data collection we are able to make comparisons with previous years and comment on the overall direction in how NHS-commissioned services are responding to the challenge of meeting the learning disability improvement standards.

Despite the opportunity for face-to-face healthcare appointments reducing in the early spring due to the pandemic, participation in the service user survey remained consistent with previous years. Most respondents reported they were treated with respect, felt safe and would recommend the service they received to a friend or family member. Overall, organisational data suggests progress is being made across NHS trusts in meeting the learning disability improvement standards. While further improvement is required in relation to some measures, in comparison with previous years increased numbers of

trusts are establishing the right systems and structures to deliver high quality services to people with a learning disability and autistic people.

Key areas of progress in meeting the improvement standards are summarised below.

Respecting and protecting human rights

Compared with previous data collections, more trusts, of all types, reported having systems to ensure enhanced contact, liaison and monitoring of people with a learning disability who are on waiting lists. Also, there was greater reported use of flexible appointment systems and more trusts specifically monitored hospital readmission rates of people with a learning disability. Fewer patient safety incidents and serious incidents requiring investigation concerned people with a learning disability.

More trusts providing universal services reported using accessible appointment letters and domiciliary visits as alternatives to outpatient department attendances. People with a learning disability reported improved availability of accessible information in situations where they wished to raise a concern or make a complaint; and trusts reported more widespread use of NHS England's Ask Listen Do resources, which Support organisations to learn from and improve the experiences of people with a learning disability and autistic people. More trusts providing universal services now report having a clear policy context for any use of restrictive practices.

Trusts providing specialist services for people with a learning disability reported having increased capacity to segment data concerning the outcomes and experiences of people with a learning disability, meaning they can compare these with other patient groups.

Inclusion and engagement

Compared with previous years, more NHS trusts now report having dedicated positions on their boards/subcommittees for people with a learning disability, autistic people or family members. Also, more reported that they engage with people with a learning disability, autistic people and families, and involve them in checking service quality and other quality improvement initiatives.

Workforce

Trusts of all types reported having greater availability of learning disability and autism awareness training than in previous years; and a higher proportion of staff surveyed

reported they had accessed such training. People with a learning disability and autistic people who had experience of using services were more involved in staff induction programmes.

More trusts reported they had enhanced the focus on recruitment and retention of specialist learning disability practitioners in their workforce plans; as well as the development of new staff roles. Among acute providers, there was evidence of modest increases in learning disability liaison staffing establishments.

Specialist services

An increased proportion of staff working for trusts providing specialist services for people with a learning disability and autistic people reported their trusts had developed new ways of supporting people in community settings. In support of this, more community-based intensive support teams are now operating seven-day services.

Trusts providing specialist services made fewer safeguarding referrals and received lower proportions of complaints concerning the care and treatment of people with a learning disability and autistic people.

There was evidence of improved auditing around the use restrictive practices in trusts providing specialist services; and in trusts where restraint is used, more reported producing annual reports on restraint reduction and making these available in an accessible format. A greater proportion of trusts now report holding risk assessments for all the restraint techniques taught to their staff.

Below we summarise, for each of the improvement standards, the headline indicators of good performance, as well as those areas where further improvement is required. This provides a national overview of services delivered to people with a learning disability and autistic people, and their compliance with the improvement standards. Individual NHS trusts and other organisations who participate in the benchmarking exercise all receive bespoke individualised reports to help them understand their particular improvement needs and develop local improvement plans.

More detailed data from the organisational level, staff and service user surveys is given in the appendices (published separately) and all three years of data for the improvement standards can be found on the online interactive toolkit in NHSBN's members' area. If

you require a log in, please get in touch with the support team at nhsbn.nhsildsupport@nhs.net		

Standard 1: Respecting and protecting rights

All trusts must ensure that they meet their Equality Act Duties to people with a learning disability, autism or both, and that the wider human rights of these people are respected and protected, as required by the Human Rights Act.

To perform well against Standard 1, trusts must be able to demonstrate that reasonable adjustments to their pathways of care have been made for individuals with a learning disability and autistic people. Additionally, trusts must have robust mechanisms to identify and flag patients with a learning disability and autistic people; vigilantly monitor restrictions or deprivations of liberty; and promote anti-discriminatory practice in relation to people with learning disability and autistic people.

Table 1: Summary of performance against the 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 a learning disability, autism or both can access highly personalised care and achieve equality of outcomes.	 91% of staff in specialist services and 74% in universal services agreed they were able to identify the reasonable adjustments people with a learning disability and autistic people needed. 82% of trusts providing specialist services have policies requiring intermittent contact with people with a learning disability and/or who are autistic on waiting lists, to see if their situation is becoming more urgent. 97% of all trusts report using flexible appointment times and durations, to make it easier for people 	 59% of trusts providing universal services do not intermittently contact people with a learning disability or autistic people on waiting lists, to see if their situation is becoming more urgent. 9% of people using trusts providing universal services, and 10% using specialist services, did not have things explained to them in a way they could understand. 46% of staff in universal services felt they did not feel they had the necessary resources to meet

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
	with a learning disability and autistic people to attend. 76% of trusts providing universal services have triage processes which prioritise people with a learning disability and autistic people. 87% of people using specialist services and 89% using universal services said they felt safe when they received care from the trust; and 81% and 85% of people reported staff in specialist services and universal services, respectively, listened to them. 72% of staff in specialist services felt they had the necessary resources to meet the needs of people with a learning disability and/or who are autistic.	the needs of people with a learning disability and autistic people.
Trusts must have mechanisms to identify and flag patients with a learning disability, 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.	 82% of trusts can flag a patient with a learning disability on their electronic patient record (EPR). In trusts providing universal services, 70% of staff reported the identification and recording of a child, young person or adult with a learning disability would be documented electronically. 74% of all trusts indicated that they could disaggregate outcome data for people with a learning disability who use their services. 	On average, trusts providing universal services identified 0.3% of people with an EPR as having a learning disability. This remains lower than the number registered as having a learning disability in primary care.
Trusts must have processes to investigate the death of a person with a	100% of trusts providing specialist services and 90% providing universal services were	30% of trusts providing universal services did not meet the commitment to ensure staff trained to

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
learning disability, autism or both while using their services, and to learn lessons from the findings of these investigations.	represented on their local Learning Disability Mortality Review Programme (LeDeR) steering group. 82% of trusts providing specialist services met the commitment to ensure staff trained to deliver LeDeR reviews undertake a minimum of 2–3 reviews per year.	deliver LeDeR reviews undertake a minimum of 2–3 reviews per year. 58% of staff in trusts providing universal services and 39% in trusts providing specialist services did not agree that when a person with a learning disability or an autistic person dies, the findings from the trust investigation are shared with staff members.
Trusts must demonstrate that they vigilantly monitor any restrictions or deprivations of liberty associated with the delivery of care and treatment to people with a learning disability, autism or both.	85% of trusts providing specialist services undertook an audit of restrictive practices in the last 12 months.85% of trusts have a policy on the use of force to hold/restrain people with a learning disability or autistic people who lack the capacity to consent.	 51% of trusts providing universal services had not undertaken an audit of restrictive practices in the last 12 months. 18% of trusts providing universal services and 10% of trusts providing specialist services do not regularly audit the restrictions and/or deprivations of liberty placed on people with a learning disability and autistic people.
Trusts must have measures to promote anti-discriminatory practice in relation to people with a learning disability, autism or both.	 90% of people who used specialist services and 94% who used universal services reported they were treated with respect by staff. 77% of trusts providing specialist services routinely monitor waiting times for people with a learning disability and autistic people, and report concerns to their board regarding waiting times and number of people waiting. 	 69% of trusts providing universal services do not routinely monitor waiting times for people with a learning disability and autistic people and report concerns to the board. 75% of trusts providing universal services do not monitor and compare emergency readmission rates for people with a learning disability and the general population.

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
	 40% of trusts providing specialist services monitor and compare emergency readmission rates for people with a learning disability and the general population. On average, regardless of the type of trust, 84% of service users said they would recommend their service to a friend of family. 	11% of staff in universal services believe people with a learning disability and autistic people do not receive the same quality of care as other people.

Standard 2: Inclusion and engagement

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

Standard 2 requires trusts to demonstrate their services are codesigned by people with a learning disability and autistic people, and to ensure they feel empowered to exercise their rights. Trusts must also ensure their services are 'values led'; for example, in staff training and complaints handling using initiatives such as 'Ask Listen Do'.

Table 2: Summary of performance against Standard 2

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
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.	93% of trusts providing specialist services provide accessible appointment letters. 91% of staff in trusts providing specialist services agreed they routinely involve people with a learning disability and autistic people when making decisions about their care and treatment.	 59% of trusts providing specialist services and 66% of universal service providers did not have a dedicated post on their council of governors or board sub-committee for people with a learning disability or their family carers. 44% of trusts providing universal services do not provide accessible appointment letters. 13% of people using trusts providing specialist services and 9% using universal services said they were not told about appointments/meetings in a way they could understand. 16% of people using specialist services and 14% using universal services said they were not given a choice in how they were cared for. 58% of trusts said people with a learning disability who have multiple long-term conditions are not assigned an identified co-ordinator/key worker.
Trusts must demonstrate that their services are 'values led'; for example, in service design/improvement, handling of complaints, investigations, training and development, and recruitment.	73.5% of trusts providing universal services and 69% providing specialist services make reasonable adjustments to complaints processes, to avoid people with a learning	18% of staff in trusts providing specialist services did not feel that people with a learning disability and autistic people were routinely involved in the planning of trust services.

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
	disability and autistic people from having to do excessive amounts of form filling.	52% of people who had wanted to make a complaint about trust services said they were not given Easy Read information about how to do
	85% of trusts plan to include details of their benchmarked performance against the improvement standards in their next quality account.	so.
Trusts must demonstrate that they co- design relevant services with people with a learning disability, autism or both and their families and carers.	97% of trusts providing universal services have on-site facilities to accommodate family carers overnight.	47% of trusts providing universal services and 56% providing specialist services do not have changing places toilet facilities.
Trusts must demonstrate that they learn from complaints, investigations and mortality reviews, and engage with and involve people, families and carers throughout these processes.	48% of trusts providing universal services have arrangements to monitor rates of Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) decisions for people with a learning disability, and 37% of staff said their trust had a policy of double checking the validity of reasons for such decisions.	47% of trusts are not using 'Ask Listen Do' good practice resources to improve services for people with a learning disability and autistic people after receiving feedback, concerns and complaints.
Trusts must be able to demonstrate they empower people with a learning disability, autism or both and their families and carers to exercise their rights.	91% of staff from specialist services and 80% from universal services felt that people with a learning disability and autistic people were routinely involved when making decisions about their care and treatment.	62% of trusts providing universal services noted that members of the executive team did not meet regularly with, and take advice from, people with a learning disability, autistic people, family carers and frontline support workers who care for them.
	66% of trusts providing specialist services agreed that members of their executive team meet regularly with, and take advice from, people with a learning disability, autistic people,	28% of staff in trusts providing specialist services and 34% in universal services did not agree that their trust had policies and

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
	family carers and frontline support workers who care for them.	procedures to ensure the rights of autistic people were respected and protected.
	77% of people using specialist trust services and 80% using universal services felt that staff had listened to what their family thought.	63% of people using universal services and 57% using specialist services said it had been difficult for family to visit during a hospital stay. (Please note that experiences may have been influenced by pandemic and associated restrictions.)

Standard 3: Workforce

All trusts must have the skills and capacity to meet the needs of people with a learning disability, autism or both by providing safe and sustainable staffing, with effective leadership at all levels.

Maintaining workforce is an important challenge for the NHS. To deliver against standard 3, organisations need to demonstrate robust workforce planning, which takes account of local population needs and seeks to address the impact of shortages of some groups of specialist learning disability practitioners. They should ensure their workforce has access training and development opportunities, so as to more fully understand how to meet the needs of people with a learning disability and autistic people; and there should be effective clinical leadership and practice supervision.

 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 a learning disability, autism or both who access and use their services, as well as those who support them.	 98% of trusts providing specialist services and 93% providing universal services reported having a board-level lead who monitors the quality of service provided to people with a learning disability and autistic people. 85% of staff in trusts providing specialist services reported having access to specialist learning disability advice when they need it. 	 80% of trusts reported providing training to people who provide day-to-day care/support on how to recognise and respond to signs of emerging health problems in people with a learning disability and autistic people. 30% of staff in universal services reported not having access to specialist learning disability advice when they need it.
Staff must be trained and then routinely updated on how to deliver care to people with a learning disability, autism or both who use their services, in a way that takes account of their rights, unique needs and health vulnerabilities; how delivery of services is tailored to each person's individual needs.	89% of trusts say they provide staff with up-to-date awareness training covering learning disabilities/autism. Only 3% of staff would not recommend their trust to a friend or family member with a learning disability or an autistic person, who needs treatment.	 75% of trusts do not invite people with a learning disability or autistic people to contribute to staff induction training. 17% of staff in trusts providing specialist services said they did not receive mandatory training on meeting the needs of people with a learning disability or autistic people during the course of their work.
Trusts must have workforce plans that manage and mitigate the impact of the growing cross-system shortage of qualified practitioners specialising in learning disabilities.	90% of trusts providing specialist services and 46% of those providing universal services have a workforce plan that supports the development of new roles in learning disabilities care.	20% of trusts providing specialist services and 70% of providing universal services do not have a workforce plan that includes data on current and future issues arising from retention/recruitment difficulties in the learning disabilities workforce.

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
Trusts must demonstrate clinical and practice leadership and consideration of the needs of people with a learning disability, autism or both, within local strategies to ensure safe and sustainable staffing.	84% of trusts providing specialist services and 67% providing universal services actively involve people with a learning disability, autistic people and families in checking the quality of services being provided and developing improvement plans.	

Standard 4: Specialist learning disabilities services

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

Organisations meeting this standard are providing specialist community support to reduce the likelihood of people with a learning disability and autistic people being unnecessarily admitted to hospital due to concerns about behaviour or mental health. They will use care and treatment reviews (CTRs) to assess individuals pre-admission, to evaluate if care could be better delivered in the community and to ensure inpatient stays are as short as possible. They will follow evidence based clinical practice and conduct regular reviews of the use of psychotropic medications, in line with NHS England's Stopping the Over Medication of People with a learning disability and autistic people (STOMP) initiative. They will also have proactive programmes to reduce the use of restrictive practices.

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.	 90% of staff say their trust has in recent years developed effective new ways to support people with a learning disability and autistic people to live successfully in the community. 75% of trusts provide intensive support services. This includes crisis support for 83% of these. 67% of trusts provide community-based support for people with a learning disability and autistic people who have forensic needs. 	40% of intensive support services do not operate 7 days a week.
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.	 78% of trusts monitor target and actual discharge dates for people with learning disabilities and autistic people in hospital. 76% of trusts say they operated a dynamic risk/support register for people with a learning disability and autistic people living in the community who are at risk of admission to hospital. 	
Trusts have processes to regularly review the medications prescribed to people with a learning disability, autism or both. Specifically, prescribing of all psychotropic medication should be considered in line	93% of trusts are signed up to STOMP.86% of trusts have signed the STOMP pledge.	32% of trusts do not have a policy to safeguard people with a learning disability and autistic people from the inappropriate prescribing of psychotropic medication.37% of staff do not agree that people with a learning disability and autistic people are fully

Improvement measure	Performance against indicators of a good service	Indicators of areas for improvement
with NHS England's stopping over medication programme (STOMP).		involved in reviewing the appropriateness of their psychotropic medications.
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.	 78% of trusts reported monitoring target discharge and actual discharge dates for people with learning disability and autistic people. 79% of trusts confirmed their healthcare practitioners continue to provide care coordination where a person with a learning disability is admitted to an out-of-area inpatient service. 	
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.	 93% of trusts have restraint reduction programmes/policies, and 76% of these had reviewed them in the preceding 12 months. 92% of trusts say they hold risk assessments for every individual physical restraint technique taught to staff. 75% of trusts publish an annual report on restraint use and reduction programmes. 	 28% of staff do not agree they have received training on reducing the use of restrictive interventions. 32% of trusts have not involved people with lived experience in developing restraint reduction policies. 57% of trusts do not have an accessible version of their reports concerning the use of restrictive interventions.

Contact us:

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If you have any questions about this report or would like to be involved in shaping the data collection, please contact the NHSBN support team at nhsbn.nhsildsupport@nhs.net

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