



Learning Disability and Autism Strategy 2024 - 2026

Working together to ensure accessible and
high quality care for patients with a learning disability

Background

People with a learning disability and autistic people experience health inequalities across the NHS. In 2007, Mencap released a report titled *Death by Indifference* that detailing six case studies where people with a learning disability did not get the care that they needed and died because of it. A number of enquiries and investigations followed including the *Six Lives* report in 2009 that investigated the services provided to the six people with a learning disability who died. In 2012, Mencap published a report detailing a further “74 Lives and Counting” contributing further to the mounting evidence that people with a learning disability were not getting equitable care and treatment.

This culminated in the Confidential Inquiry into the Premature Deaths of People with a Learning Disability (CIPOLD Report 2013). This report investigated the care of all people with a learning disability over the age of 4 across a two year period, covering five primary care trusts. 247 deaths were reviewed findings that 43% of deaths were unexpected (e.g. myocardial infarction), and 42% of deaths were premature (e.g. without a specific event forming part of a pathway leading to death). Most importantly, a lack of reasonable adjustments is a key contributor to health inequalities.

What is undeniably clear is that people with a learning disability suffer health inequalities across the NHS. A key reason for this is diagnostic overshadowing, which is when a health professional assumes that behaviours are due to the individuals learning disability rather than being a sign of pain or illness. This can lead to delays, or in some cases a complete lack of intervention. Another reason for this is a lack of reasonable adjustments being made.

Since 2016, the Learning from Deaths Review Program (LeDeR, 2016) has provided crucial insight into the key areas that contribute to health inequalities, and the findings enable trusts to focus their efforts on improving areas of care that will have the most impact to patients with a learning disability.

In the past few years Kingston Hospital has prioritised improving the care they provide patients with a learning disability by establishing an acute learning disability liaison team who work onsite directly with patients and staff.

In addition, Kingston Hospital completed the Learning Disability Benchmarking Activity in 2021 which provided feedback directly from patients, carers and staff on what the most important areas to improve are. It also detailed which areas the trust is performing equivalently to the national picture, better than other areas nationally and also where we perform poorer than other hospitals. Key areas included; making waiting areas for sensory friendly, improving knowledge and awareness, ensuring staff have the experience and resources they need, working closely with the carers of people with a learning disability or autistic people, and bettering how staff communicate with patients.

The CQC in 2022 conducted a review of the experiences of people with a learning disability in hospital, and found that improvements need to be made to enable; better access, better provision of reasonable adjustments, better communication, and better patient involvement in their own care.

Across Kingston and Richmond there are over 1,367 people on the learning disability register. The register represents just a subset of the population, with approximately 2.16% of the population being individuals who have a learning disability, whereas NHS Digital indicates that only 0.5% of patients were on the register in 2021-22.

NHS Digital in December 2022 released statistic on the health and care of people with a learning disability. These findings indicated that 71.7% of patients with a learning disability had a health check and that this is a decrease since the year previously (75.2%). NHS Digital data shows that key areas of focus within primary care should be; cancer screening, psychotropic prescribing, and epilepsy.

As earlier mentioned, health inequalities can exist due to diagnostic overshadowing. Another source of health inequalities is around fears and phobias. It is estimated that 1 in 6 people with a learning disability have a fear of medical care, this includes needle phobia. Needle phobia has been a priority amongst Kingston, Richmond and Hounslow and there have been significant efforts to introduce needle desensitisation work within the community to make vaccinations during the COVID-19 pandemic accessible to patients with a learning disability who are fearful of blood tests. This important work continues to be a priority in Hounslow.

This strategy will be the first joint strategy produced jointly by the acute and community subject matter experts. The purpose of this strategy is to guide our continuous efforts to improve the quality of care as we strive to build the foundations of an accessible and safe system for people with a learning disability.

Who are the teams?

This strategy has been written by the Acute Learning Disability Liaison Lead at Kingston hospital with collaboration from the Hounslow Community Learning Disability Healthcare Team Lead. This strategy has had input from learning disability nurses, speech and language therapy specialists, and patient experience colleagues. The community team is made up of multi-disciplinary specialists including community learning disability nurses, dietician, psychiatry, clinical psychology, speech and language therapy, physiotherapy, occupational therapy and positive behaviour support practitioners. They work with individuals who are over the age of 18 and who may have difficulty managing their health needs independently.

The Acute Learning Disability Liaison Team at Kingston Hospital are a multi-disciplinary team who work across the hospital to help staff deliver person centred and flexible care that meets the complex and unique needs of patients who have a learning disability. They are a multi-disciplinary team made up of a learning disability liaison practitioner, and a registered learning disability nurse. The teams primary goals are to facilitate integrated care by bridging the gap between acute and community, ensure patients with a learning disability are advocated for and offer education and training to staff.

Co-producing this strategy



This strategy has been co-produced with involvement and feedback from:

- Adults with a learning disability
- Adults with a learning disability and autism
- Family carer representatives of people with a learning disability
- Community Learning Disability Team representative
- Acute learning disability liaison team representative

Process of engagement:

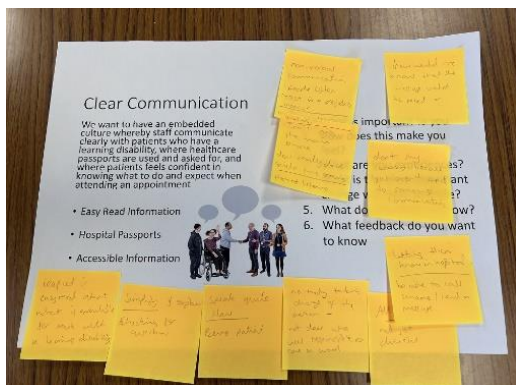
We engaged with representatives through a range of methods including; One-to-one telephone interviews, Virtual drop-in forums, Review of information from relevant and recently held engagement events, Face to face listening events held in the community, Presentation and listening at community forums and considering learning from complaints, and LeDeR reviews

A number of engagement events contributed to the production of this strategy:

- Reasonable Adjustments Listening Event Kingston WellCare Centre
- All Ages Learning Disability Partnership Board – Healthwatch Kingston
- Hounslow Community Summer Health Fair
- Accessible Information Listening Event Workshops on two occasions

Co-Production Event January 2024:

In addition, a specific listening event was held and members of the local community were invited to share their views on the strategy components. During these events we asked people with a learning disability, and listened to their feedback around what was important to them, prompting conversation to focus on the 6 key themes.



Our Key Themes

Our key themes to promote quality care for patients with a learning disability and autistic people 2024-2026

Supporting People's Needs

Training & Awareness

Digital Access

Environment

Clear Communication

Involving People

Supporting Carers

Hospital Passports

Listening to People

What is it like to come into hospital?

“Everyone needs to be treated fairly”

“anxious”

“overwhelming”

“scared”

“Need to be listened to”

“scared about being made DNAR”



Reading this strategy

Each theme has been detailed in this strategy to include;

A Title

Background Information;

These blue boxes will give the reader background on some key projects that we have been working on for some time already, and how they feed into that theme.

Objectives:

Each theme will include a list of relevant objectives that we plan to focus on.

Listening to People

Each theme also includes direct quotes from our listening events.

Each theme also has an ambition statement. The green boxes include a sentence that outlines what our ambition is for the future.

Supporting People’s Health Needs

Since January 2021 Kingston Hospital has employed a learning disability liaison service which has grown quickly; reducing health inequalities and working to ensure that reasonable adjustments are made for individuals with a learning disability. During COVID the Hounslow CLDT worked hard to ensure patients who were needle phobic had the best chance of accessing COVID-19 vaccines, by developing needle desensitisation services.

Objectives for 2024-2026:

- Ensure that people with learning disabilities have access to high quality end of life and anticipatory care in a timely way, ensuring that care plans are properly recorded and communicated across organisations. In particular, to improve awareness and use of Urgent Care Plan’s for people who are physically frail, have unstable mental health issues, are reaching end of life, and who exhibit behaviours that challenge.
- To ensure that reasonable adjustments are recorded by organisations in a timely and consistent way and that staff are enabled to deliver the reasonable adjustments that are needed.
- To improve the effectiveness of communication between organisations through clear and quick liaison between services.
- To improve the quality and effectiveness of pain assessment for people with a learning disability by improving staff awareness and availability of resources through the development of a ‘toolbox’ for clinical staff to refer to, particularly during end of life.
- To improve how we support individuals with a learning disability or autistic people who are needlephobic, and to reduce the health inequalities consequences
- To raise awareness amongst staff of the risks that contribute to increased suicide rates amongst people who are autistic, and develop staff skills in identifying when they are experiencing a mental health crisis and ensure staff know where to signpost individuals that do need support.

Listening to People:



Where we want to be:

We want patients with a learning disability to get the care that they need, when they need it, where they need it. We want people with a learning disability to be able to access services that are important to them.

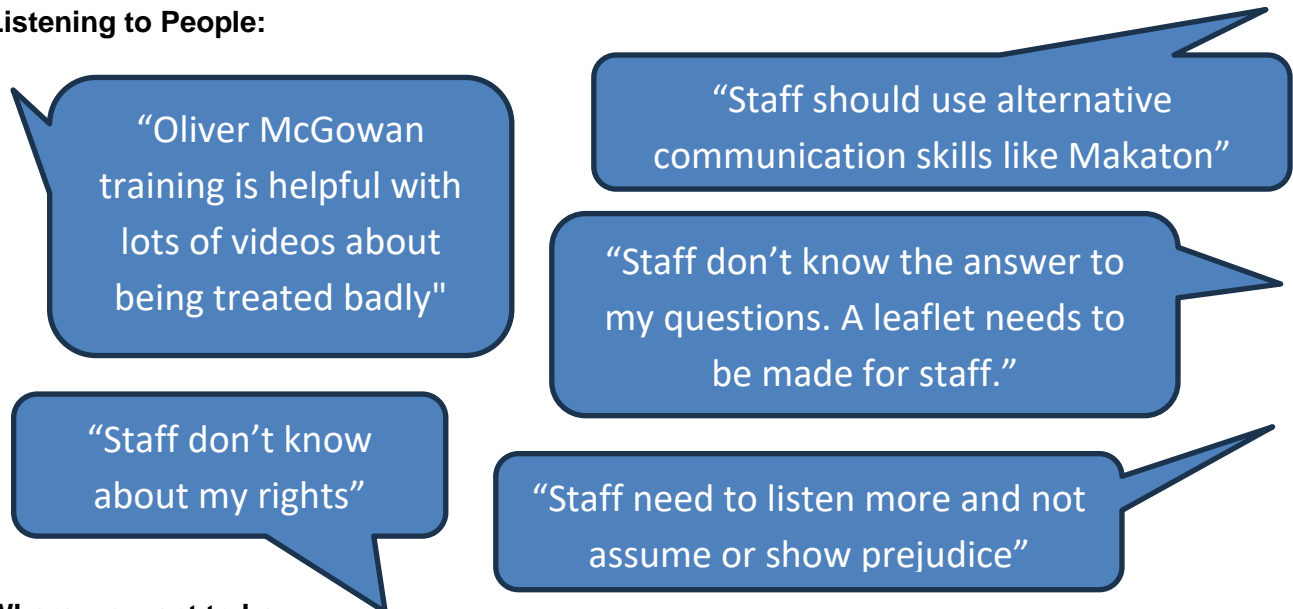
Training & Awareness

The Kingston Hospital learning disability liaison team has delivered training across the hospital MDT including on the Trust's nursing induction, F1 and F2 doctor training, Emergency Department, and many more ad hoc sessions for specialist services. However, there remain gaps as not all staff have been captured in these sessions. The Trust needs to ensure that staff are given the opportunity to upskill themselves and improve their knowledge and awareness of working with people who have a learning disability or autistic people.

Objectives for 2024-2026:

- To work with South West London ICB to facilitate the roll out the Oliver McGowan mandatory training Part 1 and Part 2 to ensure our staff improve their knowledge, awareness and confidence in working with individuals who have a learning disability or autistic people.
- To be able to monitor waiting times for KHFT patients who have a learning disability and/or autism through business intelligence reporting.
- To review and improve upon the resources that are available for staff around supporting this population well e.g. through review of 'Handy Hints' cards / abbreviations on the Acute Care Toolkit from the Royal College of Physicians.
- To improve the effectiveness and use of Hospital Passports across acute and community teams, and investigating the possibility of a standardised Hospital Passport template being created and embedded.
- To raise awareness of reasonable adjustments and to empower staff to ask about and deliver reasonable adjustments regardless of their job role.

Listening to People:



Where we want to be:

We want patients with a learning disability or autistic people to feel listened to, and understood. Staff should confidently know about hospital passports and always ask for it and read it. We want staff to feel confident to make reasonable adjustments and to do so without hesitation.

Digital Engagement

The trust has developed a patient portal that helps empower patients to be involved in their care and reduces the likelihood of missed appointments. We need to do more work to make this portal and the NHS App more accessible to patients with a learning disability or autistic people.

Improving digital access also includes making sure we provide accessible appointment letters and information leaflets that allow people with additional needs (via a carer if need be) to share information and receive information effectively as well as rescheduling appointments for easily. We want to ensure we avoid a further disadvantage to people with a learning disability or autistic people who may be non-digital.

Objectives for 2024-2026

- To promote support services available for people with a learning disability or autism (including carers/proxy users) to benefit from digital healthcare.
- To further develop our integrated online Easy Read library which provides full accessibility tools (accessible to all and not just by expert staff).
- To promote and communicate digital benefits for people with a learning disability and autism.
- People with a learning disability or autism have remote access to their own reasonable adjustments flag information as part of their health record.
- People with a learning disability and/or autism are at the forefront of digitisation with their needs anticipated by IT systems designers.

Listening to People

“I would be able to book a GP appointment on my own if I knew I would be given reasonable adjustments”

“I like being able to see just the basic appointment information: date, place, time, who I am seeing, and why.”

“It would be great if my carer could go online and change my appointment to a time when she is available to drive me.”

Where we want to be

We want our patients with a learning disability and/or autism to benefit from digital healthcare. We want patients with impairments to access key health information using technology such as the portal, and hope to see improvements in attendance and real improvements in health outcomes.

Environment

Feedback from patients with a learning disability was taken into consideration when developing the new signage across the trust. Insights were gathered including points that signs needed to be closer together on a journey, and that they needed to use simpler words without medical jargon. Kingston Hospital also had the site mapped by AccessAble to provide simple directions with photo guidance. However, there are still issues with the environment. Listening events show that a lack of quiet spaces to sit and wait can make it difficult for our patients with learning disability and autistic people.

Objectives for 2024-2026:

- To trial a Quality Checker's Scheme (a concept developed by Hounslow CLDT) with the introduction of individuals with lived experience quality checking health services on site and providing feedback.
- To ensure an accessible roll out of the AccessAble mapping of the hospital to ensure patients with a learning disability are able to access and benefit from the software.
- To develop a project plan for the next phase of improving the accessibility of staff signage through the addition of symbols and images.
- To develop stronger links between learning disability specialist services and the existing PLACE and miniPLACE environmental audit pathways across organisations.
- To expand our awareness of where there is high footfall of individuals who have a learning disability and/or who are autistic.
- To identify a network of experts by experience who can be involved in audits and represent variation across the relevant population.
- To investigate creating more sensory friendly areas within the acute hospital setting.
- To improve the entertainment offer to our patients, including those with a learning disability and autistic people

Listening to People:



Where we want to be:

We want there to be clear path for auditing and quality checking the environments across our organisations that people with a learning disability or autistic people use, by targeting high footfall areas, and evidence of continued improvement

Clear Communication

The Learning Disability Liaison team at Kingston Hospital has been working on a project to improve communication with patients with a learning disability. This included gaining funding from the trust charity, which enabled us to train staff in Makaton, purchase a talking mat, training a staff member in using the talking mat, and also is facilitating the development of an easy read library. However, feedback from patients still indicates that the hospital doesn't always communicate well particularly with outpatients. For example, patients with a learning disability do not get easy read appointment letters and sometimes say that they can't understand the letters they do get.

Objectives for 2024-2026:

- To develop a shared bank of Easy Read Information made available to all staff.
- To ensure that staff have the skills and resources to communicate with individuals who have a learning disability and communication impairments.
- To promote the use of the healthcare/ hospital passport to improve staff utilisation.
- To work jointly with the patient experience team to support delivery on Accessible Information Standard quality improvement priority.
- To work collaboratively to empower patients and family members in preparing for health appointments through offering clearer guidance.
- To ensure we communicate well between services and departments, particularly between paediatric and adult services regarding patients with complex needs, learning disability and/or autism who are transitioning to adult services.

Listening to People:

"Don't shy away because you aren't used to someones communication"

"Speak quite slowly. Be patient with us"

"Non-verbal communication is really important"

"Don't use jargon"

"Recognising that noises may be the way someone communicates"

Where we want to be:

We want to have an embedded culture whereby staff communicate clearly with patients who have a learning disability, where healthcare passports are used and asked for, and where patients feel confident in knowing what to do and expect when attending an appointment

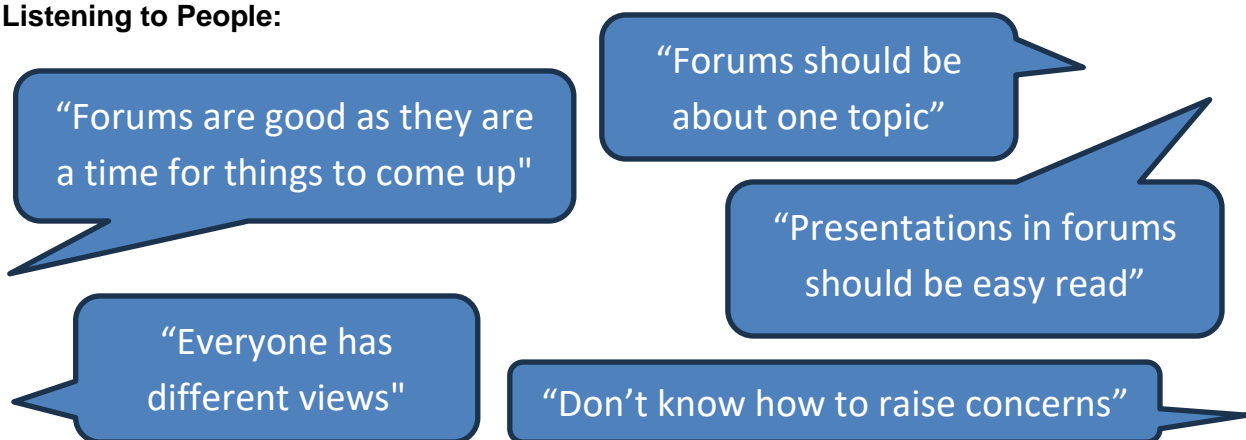
Involving People

Hounslow CLDT co-organised and delivered a health fair for people with learning disabilities in partnership with Certitude, LBH/NW London ICB (in follow up to learning from an event sharing the learning from lives and death reviews, held in November 2022). Kingston Hospital took part in the Learning Disability Benchmarking Activity and developed an Easy Read report detailing the experiences of patients with a learning disability and staff. A listening event was held in the community and people with lived experience attended and shared their experiences of coming to hospital. We want to develop on this work and ensure that there is an integrated culture that enables the voice of people with a learning disability or autistic people to be heard.

Objectives for 2024-2026:

- To work closely with South West London organisations to ensure an effective and timely roll out of the Oliver McGowan mandatory training.
- To embed the Ask Listen Do program across our organisations by increasing awareness of the concept.
- To create a regular forum where we can ask, listen and then hear ideas and suggestions on a regular basis from the local community of people with a learning disability and autism. We want the forum to be co-chaired and co-presented by people with lived experience.

Listening to People:



Where we want to be:

We want there to be a well established process whereby experts by experience are consulted and feedback is gathered. This supports the principles of Ask Listen Do and enables decision-makers to hear the voices of people with a learning disability or autistic people.

Supporting Carers

Kingston Hospital has developed a Carers Policy and a Carers Liaison Service was launched in 2023 which has quickly raised awareness of carers' needs received many referrals. The carers liaison service reach out to unpaid carers and offer signposting and help accessing increased support where needed. Kingston hospital has a clear compassionate and therapeutic visiting policy, ensuring that carers (both paid and unpaid) are allowed to stay with their loved ones without restricted visiting times where appropriate. There is also the Carers Passport, a card which can be signed by suitable staff that allows a carer unlimited access to wards as well as a discount on food in the canteen. There is increased work being completed to join up carers support across acute and community services.

Objectives for 2024-2026:

- To ensure that the unique needs of carers of individuals with a learning disability or autistic people are considered within the wider carers project through representation from specialists or individuals with lived experience.
- To engage with community stakeholders to ensure that the needs of unpaid carers and their feedback is recorded and shared, and that gaps in support are identified.
- To expand our support for our own staff working at Kingston Hospital who are parents or family carers of people who have a learning disability or autistic people and identify ways to harness their unique and specialist insights into how services could be improved.
- To take steps to increase the support for the carers or families of young people going through the transition from paediatric to adult services.
- To embed new legislation regarding unrestricted visiting for individuals when they are in hospital

Listening to Carers:

"The information transfer from hospital to care home...thinking about how we handover to new care homes"

"Giving information to people needs to be better"

Where we want to be:

We want carers to feel supported and cared for, and that their wellbeing is important to us. We also want staff carers experiencing the challenging of caring for people with a learning disability and autism are reassured, supported and listened to.

Hospital Passports

There was so much important and interesting discussion about hospital passports at the listening event and it was important to share that in an additional section of this document. Experts with lived experience shared their thoughts and ideas:

“Can there be an electronic hospital passport?”

“Staff/family struggle to find time to fill one out”

“Keeping them up to date is hard”

“They don’t always come back from the hospital”

“Ask someone to bring their hospital passport in appointment letters”

“The first thing someone should ask a patient when they are in hospital is can they see the hospital passport”

How will we monitor and measure change:

- Feedback on key areas of the strategy will be gathered through stakeholder meetings and strong community partner links with advocacy organisations such as;
 - Kinston Involve
 - All Ages Learning Disability Partnership Board
 - Mencap Kingston
 - Kingston Carers Network
- The Learning Disability and Autism Steering Group will provide senior oversight so that progress against the objectives can be monitored and any barriers and challenges identified, recorded and troubleshooted where possible.
 - A workplan is held within this group and projects are monitored and presented at the bimonthly group.
- The National Benchmarking Activity will continue to be an important method of surveying different stakeholders, patients, staff and comparing the organisations performance in comparison to others.

Listening to lived experience experts on how they want feedback:

“How many people are using hospital passports with numbers”

“Surveys”

“Ask patients once during their stay and once after their leave about their experiences

“Send out a newsletter email in easy read to everyone”

Key messages and values

This strategy has been developed with a flexible and adaptable approach so that the themes and actions reflect what our local community of people with a learning disability and/or autism, or their carers have to say about their experiences of receiving healthcare. These themes all align with the values and strategic objectives of Kingston Hospital NHS Foundation Trust and Hounslow and Richmond Community Healthcare Trust.

The themes also contribute to meeting the wider strategic objectives of the new Better Together partnership between Kingston Hospital NHS Foundation Trust and Hounslow and Richmond Community Healthcare. The seven themes described for this Learning Disability and Autism strategy link to key objectives and priorities of the better together partnership. Such as;

Reducing Inequalities

As a hospital and community service we want to reduce inequalities for all our patients. This learning disability and autism strategy will help us do that through the key themes such as Supporting People's Needs, and Training & Awareness. Projects will include work on identifying an individual's reasonable adjustment needs at the first contact point with any health service, sharing the information effectively across providers in social care and health and meeting these needs. Hospital and community services are also working together to ensure our staff do the full Oliver McGowan Mandatory training.

Improving our Digital Capabilities.

We also want to improve how our digital and computer systems work for all patients. To improve this for our patients with a learning disability and autism we will be guided by our 'Digital Access' theme in the learning disability and autism strategy. Projects will include ensuring we record, flag, deliver and share reasonable adjustments and that the hospital's digital portal and online access and information provided to patients across acute and community services is more accessible for all.

Better experience of hospital and community care for all:

We want all of our patients to have a better experience of care. To ensure we meet that objective for patients with a learning disability and/or autism we will be focusing on key themes such as end of life care, clear communication, and improving our environments. This will include information sharing projects such as strengthening our use of urgent/ universal care plans, being better at assessing pain, and identifying ways we can make environments more accessible and sensory friendly.

Services working together to help young people to become adults:

We recognise that for any young person who needs hospital care, the process of transitioning to adulthood is often a frightening time full of uncertainties. We will aim to explore how we can better support young people who have complex needs including learning disability and/or autism as they transition from paediatric to adult services.

You can read more about the Kingston Hospital and Hounslow and Richmond Community Healthcare Better Together Strategy for 2024 – 2029 on the website [here](#).

Ensuring our strategy is delivered

In order to make this strategy a reality, there needs to be clear mechanisms to oversee delivery. The executive lead for learning disability is Nicola Kane Chief Nurse, and the clinical lead is Berenice Constable.

The Learning Disability and Autism Steering Group consists of a core membership of clinical leadership and subject matter experts from across Hounslow Learning Disability Team, Your Healthcare and Kingston Hospital Foundation Trust who will meet bi-monthly and monitor progress of projects and improvement work.

Review

This strategy will be reviewed in November 2026 in order to ensure it remains relevant to our aims and objectives and to refresh the strategy for 2027-2029.

Special Thanks:

We would like to say a special thank you to all the people who took the time to come to our listening events. Thank you for sharing your thoughts, feelings and experiences. This feedback was crucial in helping us develop a strategy that reflects our patients' priorities.

Many thanks to:

- Involve Kingston
- Healthwatch Kingston and the All Ages Learning Disability Partnership Board
- Achieving for children job coaching program