Report & Recommendation Response Form

Report sent to	**Ciara Mackay, Director of Nursing, Safeguarding Adults, Vulnerable Adults & Patient Experience**
Date sent	**28 May 2024**
Report title	**Guy's and St Thomas' NHS Foundation Trust (GSTT) response to Healthwatch Southwark report:** Empowering voices: Examining healthcare access for adults with learning disabilities and autistic adults in Southwark, June 2024
	Response (If there is a nil response please provide an explanation for this within the statutory 20 days)
Date of response provided	**20 June 2024**
Please outline your general response to the report including **what you are currently doing to address** some of the issues identified.	• We welcome the publication of this important report, its findings and recommendations as we continue to focus on improving the accessibility of the hospital and community services we provide across a number of important areas. • We have carefully considered each of Healthwatch report recommendations whilst also developing implementation plans for specific actions against a very challenging background of competing demands and priorities for our staff and senior managers in this ever-changing NHS landscape we operate in. • The Trust recognises that systematic, unfair and avoidable differences in healthcare are present across society and within the populations that we serve. We are committed to ensuring that all people who use of our services have equal access to high quality care, and that their experiences and outcomes are as positive as possible. • For people with learning disabilities and autistic people who access our services, we know more needs to be done to improve the quality of support we provide to them. As a healthcare organisation, we do not always understand their individual needs and misinterpret their behaviour. • This report is an important resource for us as it provides learnings and further evidence of the barriers that prevent adults with learning disabilities and autistic adults from accessing healthcare. It provides a holistic picture of difficulties these patients face and we can see that the findings and recommendations apply to services across our Trust.

	• Colleagues across the Trust have contributed to our response, including, adult and children's services that provide care to patients who have learning disabilities or are autistic. We have considered the recommendations proposed by Healthwatch and implications for services at Guy's and St Thomas' NHS Foundation Trust. • The following sections (pages 2-10) provide an overview of ongoing work and emerging initiatives at GSTT, in response to the findings and recommendations of the report.
	Please outline what **actions** and/or improvements you will undertake **as a result of the report's findings and recommendations**. If not applicable, please state this and provide a brief explanation of the reasons.
Trust response on recommendation 1: Training	**Oliver McGowan Mandatory Training on Learning Disability and Autism** • We have introduced the Oliver McGowan national mandatory training on learning disabilities and autism which is designed to assist staff and employers across health and social care in having better skills, knowledge and understanding of the needs for autistic people and people with a learning disability and its vital importance. • This training was launched across the organisation in December 2023. The Trust was asked to achieve 10% compliance by March 31st and achieved 19.3%. • The Trust is required to implement face to face training for both Tier 1 (1 hour) and Tier 2 (1 day) to follow the eLearning training. The Trust College of Healthcare is working with national and South East London colleagues to implement this. • In addition, bespoke ad hoc training is delivered in key areas which provide care to patients with learning disabilities. This training includes communication and reasonable adjustments. **Events** • The Trust's Community Services for Adults with Learning Disabilities team and other Trust services regularly support and facilitate public events, such as the Learning Disabilities Awareness Week, Ortus learning disabilities event, GSTT Neurodiversity Celebration Week, Big Health Week, St Thomas' hospital stalls, Southwark showcase event.

	LDA Champions • The Trust's Learning Disabilities Committee brings together champions from across the Trust including Evelina, Women, Medics, Allied Health Professionals, Nursing staff as well as specialist such as Acute LD liaison nurses and Community Learning Disability Teams. • The Trust all-age autism strategy development, brings together people with lived experience, staff, partners and local community organisations who will help to shape the strategy.
Trust response on recommendation 2: <u>Sharing information</u>	**Liaising and sharing learning and best practice with other mainstream services to improve our services and help implement adjustments** • The Trust uses findings from reviews such as the annual learning disability and autism NHSE benchmarking which includes surveys of patients, carers and staff and the Learning from Deaths of adults with learning disability and autistic adults Review (LeDeR). • LeDeR is a service improvement programme which aims to improve care, reduce health inequalities, and prevent premature and avoidable deaths of people with a learning disability and autistic individuals by reviewing information about the health and social care support people received before their death. **Complaints** • Complaints can be made to any staff member and/or by accessing the Trust's Patient Advice and Liaison Service (PALS). One of our key actions is to improve the accessibility of the complaints process to make it easier for adults with learning disabilities and autistic people to make complaints. **Improving access to quality and inclusive services** • As part of developing the Trust's new all-age autism strategy (for more detail please see page 10), we have developed areas of focus (workstreams) informed by national and South East London guidance. • One of these key areas of focus is on improving access to quality and inclusive services. We will work with autistic people, their families, carers and community networks to improve access to services for those who need extra help, to enable them to find reliable information and access services in a way that suits them. This involves ensuring that reasonable adjustments being made available in our services as well as autism specific support.
Trust response on recommendation 3: <u>Communications</u>	**GSTT project to develop feedback tools for patients with learning disabilities** A group of GSTT colleagues with a special interest and expertise in working with adults with learning disabilities have been working together to develop tools to capture feedback from adults with

learning disabilities across different care settings (in our hospitals, specialised outpatient services and in the community). The group has developed and tested easy read questionnaires that use picture symbols chosen by service users.

- A staff training package has been developed to give people the skills they need to use the questionnaires with service users. As part of this training, a small number of our staff have received training in Makaton. It is our aspiration to increase the number of staff who receive this training.

- The tools are working well in community clinics and ideas for improvement have been identified from service user feedback. Tools are now being trialled in services within our hospitals.

Visual support
- In response to the Healthwatch report recommendation on PECS (Picture Exchange Communication System), the Trust recognises the importance of such a system which can be used as well as other augmentative and alternative communication (AAC) systems for those people with limited to no verbal language skills to express a distinct need. PECS is useful if the person has been exposed to it previously.

- The Trust utilises a wide range of visual support tools such as objects, photos, symbols and key word signing to support both receptive and expressive communication needs of our patients and clients.

GSTT project proposal to improve patients experience of contacting the Trust
- Reflecting feedback from our patients, we know that ease of contact is one of the highest areas of concern and directly affects the people's experiences of interacting with our services.

- The Trust's Centre for Innovation, Transformation and Improvement, are in the early stages of developing a proposal to improve the patient experience of contacting the Trust by telephone. It aims to address the challenges faced by patients and services and explore opportunities for improvement. We will update Healthwatch colleagues on this work through quarterly liaison meetings.

Other methods of communicating with the Trust
- The MyChart app (our online app that enables patients to securely access parts of their health record with us, giving them more control over their care) provides patients and service users with an alternative way of communicating with services regarding

appointments. It provides direct access to information about appointments, care and treatment.

- Service users can cancel appointments and add a note of the reason for this and the clinical team will call them to re-arrange. Service users can also use MyChart to view summaries of hospital visits, discharge letters and details of medicines that may have been prescribed following their hospital visit or stay. The app also lists past, current and future appointments so that service users have an overview of their care journey.

- If the service user has a carer who supports them with managing their care and hospital appointments they can invite their carer to have "proxy access" to their MyChart account. This enables the carer to see what the service user sees and helps them to manage things such as appointments and medications. If the patient cannot consent to proxy access this would be a decision only as a best interest decision involving multi-professional colleagues and carers / family as appropriate.

Web-accessibility
- We have worked with people with disabilities to design and test our new website to make it as accessible as possible regardless of background, ability or needs. This co-development approach was a key driver behind how it looks and works.

- The Trust provides a comprehensive language and accessible support service to meet the communication needs of our diverse population. Our website, that also includes a separate Easy read section, has been designed to ensure everyone can access the information they need, regardless of background, ability or needs.

- As a healthcare organisation, we understand how important it is for our patients and the people who care for them to easily access and understand the information they need. We are committed to making sure as many people as possible are able to use the website. For example, that means people should be able to:

  – Change colours, contrast levels and fonts using browser or device settings
  – Zoom in up to 400% without the text spilling off the screen and without content being truncated or overlapping
  – Navigate most of the website using a keyboard or speech recognition software
  – Listen to most of the website using a screen reader (including the most recent versions of JAWS, NVDA, Voiceover and Talkback)

	• We follow best practices and evidence-based guidance such as the NHS content style guide to make the wording on our website as simple to understand as possible, and continue to review content so it's written in plain English. There is advice available online to help people make their device easier to use if they have a disability, including from the AbilityNet charity.
	
	• We were the first trust to roll out the 'Sunflower lanyard' initiative to support patients and staff with hidden disabilities, and the first to install state of the art 'changing places' facilities - which have now been introduced at all our hospital sites.
	
	Digital Inclusion
	• At Guy's and St Thomas', we are committed to making sure that people who are unable to use, or who choose not to use, digital services are not disadvantaged. Digital inclusion involves:
	
	  – Digital skills: being able to use digital devices (such as computers or smartphones) and the internet
	  – Connectivity: access to the internet through broadband, wi-fi and mobile
	  – Accessibility: services need to be designed to meet the needs of all users, including those dependent on assistive technology to access digital services
	
	• The Trust is currently developing the digital inclusion framework to:
	
	  – Address digital exclusion across the Trust for patients, their families and carers
	  – Make sure that all our staff are equipped with the essential digital skills, capabilities and behaviours they need, to provide the most effective and compassionate care for all and to succeed in their own careers.
	
	• We have partnered with the organisation, ClearCommunityWeb, to help us reach our communities by providing training and expertise to support people (including older people, vulnerable adults, people with accessibility needs and carers) feel more confident and comfortable with technology through workshops and individual support.

Trust response on recommendation 4: <u>Operational issues</u>	**The Reasonable Adjustments Digital Flag (RADF)** • The Reasonable Adjustment Digital Flag is a national record which indicates that reasonable adjustments are required for an individual and optionally includes details of their significant disability or impairment, underlying conditions and the reasonable adjustments that should be considered.

- Since September 2022, the Trust has been participating in the NHS England Reasonable Adjustment Fast Followers Pilot to ensure that we are in a position to support this initiative. Work is underway to develop the reasonable adjustments digital flag within our new EPIC system (our electronic health records for patients). We will ensure these technological advancements align with NHSE national standards and effectively enhance service delivery for people with learning disabilities and autistic people.

- Leads from our electronic health record system are liaising with NHS England to support the build of the flag. Adults with learning disabilities have been involved in piloting this work.

Accessibility and reasonable adjustments to service provision
- In the Trust's Adult Community Learning Disability Service, we contact the individual and/or carer as appropriate and arrange to meet them at their home or another place based on their individual needs and preferences. We provide a face-to-face interpreter If required.

- Following a referral, we liaise with patients, families, carers, other form of guardianship when required (depending on individuals need e.g. high functioning patients) to determine what level of support is required.

- We use easy-read information, i.e. letters with the clinician's photograph, contact details and social stories, to explain to the patient what to expect when accessing a specific service they need, or for information about their condition and what they need to do next.

- We recognise the challenge with providing accessible information that covers every need. The work underway on the bespoke reasonable adjustment digital flag (as described on page 6- Reasonable Adjustments Digital Flag- relevant section) will also support this.

- As a healthcare provider we expect staff across all our services, in our hospitals and in our communities, to be aware of and understand the need to provide reasonable adjustments when patients are admitted to our inpatient facilities or attend clinical and outpatient appointments.

Developing the new Carers Strategy
- Putting patients first and Respecting others are two of the Trust's core values. These apply not only to the way in which we care for, treat and support our patients but also the way in which we interact with carers and families who provide many hours of unpaid support to our patients

- The Trust recognises the vital contributions that unpaid carers make to patient care by sharing expertise and knowledge they can share on patient's needs and preferences. These can provide additional insight and contribute to a better patient experience.

- We propose to focus on four areas:

1. **Identifying and increasing the visibility of carers**
   We will work with partners to identify carers as early as possible in the patient journey; We will ensure carers details are recorded on electronic health records system; develop a badge/lanyard for carers.
2. **Supporting and identifying carers needs**
   We will signpost carers to agencies that carry out an assessment or offer support; We will ensure that carers have the support they need to support patients through their patient pathway (including discharge); We will offer flexibility when booking and rescheduling appointments for themselves and the person they care for.
3. **Working in partnership with carers**
   We will ensure carers are involved in decisions about patients care where appropriate; We will communicate clearly and signposting patients to clear, current sources of information.
4. **Enhancing skills through training**
   We will work with carers to identify any skills development needs and co-design training and preferred methods of delivery; We will focus on raising the awareness of the role and needs of carers for Trust staff.

Modernising our infrastructure
- As a healthcare organisation, we know our hospital settings and physical environment itself can cause sensory distress as it can be chaotic noisy and unfamiliar to people with learning disabilities and autistic people.

- Following work that was carried out as part of developing the Trust's new organisational strategy, we have identified strategic priorities that include our commitment to modernising our infrastructure:

  – We will significantly improve the resilience, reliability and user-experience of our existing physical estates, making sure we get the basics right for patients, visitors and staff.

Population Health and Health Equity
- The Trust is committed to delivering our vision to address health inequalities, patient outcomes and patient experience. We are in the early stages of developing a Trust vision for population health

and health equity, with our partners, which will outline how we intend to achieve our ambition to improve the health of our populations and the key areas which we will focus our delivery on to do this.

- The Trust's emerging Population Health Management hub, will drive this vision forwards using data to support clinical services to identify a population health improvement focus, develop evidence-based interventions and evaluate the long-term impact on overall outcomes and reduce inequalities.

- Building healthier communities as an 'anchor organisation': The Trust plays an important role as a local 'anchor organisation' (which means that our long-term sustainability is tied to the wellbeing of the populations we serve). We will support local communities in a number of ways, including providing access to high quality training and employment.

Equity of service delivery
- We are constantly striving to ensure that our services meet people's needs, regardless of their age, disability, ethnicity, sex, religion or beliefs, gender reassignment, sexual orientation, pregnancy and maternity, and marriage or civil partnership, in accordance with the Equality Act 2010 and our Public Sector Equality Duty.

- The Trust is committed to safeguarding patients, including people with learning difficulties and autistic people, who may be vulnerable.

- We participate in our local, multi-agency safeguarding boards which aim to safeguard vulnerable people through a partnership approach.

Equality Impact Assessments (EQIA)
- We undertake equality impact assessments to identify and mitigate possible impacts of implementing a project/ change, on individuals and groups who identify with protected characteristics, and to provide assurance that our policies, functions and services are fair and equitable and help drive service level improvements.

- We are redesigning our EQIA process and form so ensure that equalities are considered early in a project, policy or service change journey, in order to shape and inform the solution, and to plan engagement activities and mitigations or any differential impacts.

	Widening participation
	• The Trust has a strong commitment to its widening participation strategy, working with local schools and colleges, community groups and other partners to support local people from all backgrounds into the workplace. This includes initiatives such as:
	   – An internship programme to help build the experience and independence of young people with autism or learning difficulties. Many former interns are now valued members of staff.
	   – The Department of Work and Pensions sector-based work academy programme, which provides people with access to entry-level roles and important skills for future employment.

Additional Trust programmes of work underway that respond to the findings and recommendations of the HWS report)	**Trust all-age Autism Strategy** • As a healthcare organisation, we have a duty to involve people and communities in developing and planning services and strategies. We are committed to listening to and acting on the experiences and aspirations of communities to improve services. • We are working with colleagues across the Trust, key stakeholders, partners, local community organisations and with ongoing executive leadership support, to develop the Trust's new all-age autism strategy. • This work represents our loudest commitment and a significant step forward in ensuring that every autistic person, regardless of age, has access to the support and resources they need when they access and use our services. • The strategy will set out our organisational vision and long-term strategic framework to ensure that we provide outstanding, consistent, equal and accessible care for all autistic people (adults, children and young people). • To develop a truly representative and effective strategy, we are committed to co-developing the strategy with autistic people, their families, carers, and various community organisations. • Through this work we want to make GSTT a more autism-friendly and inclusive healthcare organisation that delivers a positive experience for all autistic people accessing our services.
Signed	**Ciara Mackay**
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