



London Ambulance Service NHS Trust

Providing high quality care across London for Autistic people

Trust Strategy 2023-2026

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Background

In September 2023, the LAS launched its new five-year strategy. We consulted widely with our patients, partners, and other members of our organisation to find out how they would like to see us grow.

As an organisation we have evolved from what is sometimes thought of as the classic ambulance service that only transports sick patients to hospitals. We are an ever-more-skilled labour force capable of providing a vast array of urgent and emergency clinical assessments on-site as well as over the phone.

As part of this work, we examined demographic patterns and conducted a future horizon scan to identify potential advancements in pre-hospital care.

One of the most important themes to emerge was the need to provide more individualised clinical care to our patients, recognising their unique needs.

This has led to the development of this strategy; to provide high quality care across London for Autistic people. As an organisation we have a commitment to fulfil our promise to be "The Capital's Emergency and Urgent Care Responders" by offering exceptional emergency and urgent care to all residents of our city around-the-clock, however, whenever and wherever they need it.

1. What does it mean to be an autistic person?

Being an Autistic person is a lifelong diagnosis that impacts how people perceive, communicate and interact with others or their environment. This can include:

- Difficulties with social communication and interaction such as abstract gestures or communication, reciprocal conversation or recognising feelings and intentions.
- Repetitive or restrictive behaviours
- Extreme anxiety
- Meltdowns or shutdowns
- Over or under responsive to sensory based input¹

Everyone is an individual. Autistic people can have varying or complex needs and benefit from a wide range of support, some autistic people will need very little or no support in their everyday lives while others may need high levels of care. How a person benefits from adjustments or support can be impacted on by the context of the environment. It is essential to consider the impact ill health or an ambulance attendance may have on the context in which a person is functioning. Not feeling understood or accepted and not receiving the right support, has contributed to Autistic people having poorer experiences of mental health.

This was reflected in our work with Healthwatch, to identify how we as an organisation can support our patients better. It was suggested that there is room for improvement in communication training for providing care for adults with additional needs, such as disabilities or neurodiversities, and that improvements in technology could assist this, and provide added support to both the patient and clinician.

¹ <https://www.autism.org.uk/advice-and-guidance/what-is-autism>

“Service users have asked for LAS staff to have increased training on neurodiversity so that neurodivergent people have easier access to LAS services” Healthwatch Lewisham

There are an estimated 700,000 autistic adults and children in the UK – approximately 1% of the population. In addition, there are an estimated 3 million family members and carers of autistic people in the UK (National Autistic Society). As understanding of the diagnosis of “Autism” has developed, so has the expected prevalence however the expected number of Autistic people in the UK and specifically London is unreliable. There are currently large waiting lists for diagnosis, less established support networks or pathways of care and many people who have not been identified as being an autistic person.

2. National focus:

The Autism Act 2009 is the only diagnosis named policy in law². Along with two subsequent mandated government strategies aiming to tackle health and care inequalities for autistic people and improve understanding and acceptance of autism within society, there has been ongoing recognition of the need to change Autism care for the last 14 years.

During this time campaigns by national charities and advocacy organisations have raised that not enough was being done to create real change to the lives of Autistic people, with increased direction and focus being required nationally.

In 2019 The NHS Long term plan identified the crucial role health services have to play in helping Autistic people lead longer and healthier lives. This priority highlights reducing health inequalities as a primary focus of this work, ensuring those supporting Autistic people are able to effectively make reasonable adjustments to ensure autistic people “get equal access to, experience of and outcomes from care and treatment.”³

Ensuring an awareness of the needs of Autistic people is also identified as a necessity across healthcare. The initiation of national Statutory/Mandatory training in Learning Disabilities and Autism from September 2022 for all regulated services, indicates the priority identified to change care and outcomes for this patient population and the transformation in knowledge and skills required across services to do so.

Similarly the Core Capabilities Framework for Supporting Autistic People⁴ provides services with a context for baseline knowledge requirements that will ensure good practice care can be delivered. Capabilities falling under the domains of “Understanding Autism”, “Personalised Support” and “Physical and Mental Health” are relevant to all and considered pillars of baseline required knowledge. Using this framework provides organisations a blueprint from which to inform the skills, knowledge and experience they ensure their staff hold within the context of their job role. The capabilities described also act as a starting position for organisations to reflect on how and where these areas of practice are prevalent within their setting, to recognise when barriers to care may be present.

² <https://www.legislation.gov.uk/ukpga/2009/15/contents>

³ <https://www.longtermplan.nhs.uk/online-version/chapter-3-further-progress-on-care-quality-and-outcomes/a-strong-start-in-life-for-children-and-young-people/learning-disability-and-autism/>

⁴ <https://www.skillsforhealth.org.uk/wp-content/uploads/2020/11/Autism-Capabilities-Framework-Oct-2019.pdf>

The incorporation of Autistic people within the Learning Disability Mortality Review Programme⁵ in September 2021 highlights the ongoing recognition that improvements are required to services and care provided to Autistic people to reduce health inequalities and prevent premature deaths, with a firm focus on recognising the experience of Autistic people within healthcare.

Recognising these innovations nationally, and the work that is being undertaken by our partners in the London Integrated Care Systems, is an important influence in creating our strategic missions to delivery outstanding clinical care, being an increasingly inclusive organisation and contributing positively to the health of the capital.

Local need for an Autism strategy:

We understand that more patients wish to be treated at home or locally, relieving both pressures on the UEC pathway and creating a more comfortable and positive experience for the patient.

However, research suggests 80% of autistic adults experience difficulty accessing primary care services such as their GP⁶ and a high percentage are therefore less likely to seek support when required. Problems that could be identified and managed early are often left to escalate, unnoticed by health professionals or even by autistic people themselves, until a crisis is reached. Evidence suggests autistic people are therefore more likely to present with acute physical health needs and end up using emergency services and requiring hospital care than the general population.⁷

We know that autistic people often need adjustments to their healthcare for this to meet their needs, but that currently professionals cannot always identify that people are autistic or the adjustments they may require.⁸

“Adapted consultations for those having impairments is imperative to improve peoples’ experience with the service...” Healthwatch Camden

The Trust Strategy has looked to evidence this on a local level by seeking patient representative feedback through Healthwatch. The feedback we received expressed several themes around neurodiversity that highlight the need for an autism strategy. In particular, there was a focus on communication with call handlers, increase in appropriate care pathways, and awareness training^{9,10} These themes have also been raised by the Public Patient Council subgroup.

Autistic people have poorer physical health outcomes and a lower life expectancy than the general population, on average dying 16 years earlier than non-autistic people. Possible reasons for this gap include poor professional understanding of autism amongst health and care staff, which can result in autistic people having signs of illness or their needs overlooked. Without the right understanding, autistic people can miss out on adjustments needed for them to

⁵ <https://leder.nhs.uk/about>

⁶ Doherty M, Neilson S, O'Sullivan J, et al. Barriers to healthcare and self reported adverse outcomes for autistic adults: a cross-sectional study. *BMJ Open* 2022;**12**. Accessed at: <https://bmjopen.bmj.com/content/bmjopen/12/2/e056904.full.pdf>

⁷ <https://www.autistica.org.uk/downloads/files/Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf>

⁸ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004528/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf

⁹ <https://www.healthwatchkingston.org.uk/report/2023-02-02/london-ambulance-service-strategy-2023%E2%80%932028-healthwatch-kingston-community>

¹⁰ <https://www.healthwatchlewisham.co.uk/sites/healthwatchlewisham.co.uk/files/Lewisham%20LAS%20Report.pdf>

engage in medical appointments, which often leads to distressing experiences, avoiding seeking medical attention or losing out on support.¹¹

A focused strategy ensures the service acknowledges the individuality of autistic people, personalising its approach and the support people receive. It also ensures the support autistic people may benefit from is not inappropriately aligned predominantly with mental health or learning disability care.

Our Trust Strategy has four main priorities for delivering more individualised clinical responses;

- Providing a specialist individualised response
- Ensuring patients impacted by health inequality get the care they need
- Expanding the range of assessments, treatments or interventions that patients can be offered
- Reducing unnecessary emergency department attendance

These priorities are supported by the data we have reviewed. The Trust documented attending 9108 face to face visits between 1st May 2022 and 31st May 2023. It is not known however the reason for these attendance, themes of assessment or treatment provided and the patient outcomes. Consultation and working to understand this data throughout the first year of the strategy will enable the focusing of ongoing action as the strategy is reviewed on a yearly basis.

Aims and objectives of this Strategy

This strategy aligns with the Trusts five-year strategy, and explains in more detail the vision we have to support Autistic people who access the Trusts services. This includes input via our emergency or integrated urgent care services and contact with non-patient facing or operational services.

The overarching aim of this strategy is to reflect on where across the London Ambulance Service (LAS), the barriers to equal healthcare for Autistic people may exist. Through the use of open reflection, we want to explore the action we can take to create sustainable change across the service to reduce these experiences and subsequent impact on the lives and deaths of Autistic people across the capital.

We will reflect the Trust's vision through this by putting the values of caring, respect and teamwork at the forefront of our work. The Trust has three missions below which will form the key planks of this new strategy. They are:

1. Our care: Delivering outstanding urgent and emergency care where and whenever needed.
2. Our organisation: Becoming an inclusive, well-led and high skilled organisation people are proud to work for.
3. Our London: Using our unique pan-London position to contribute to improving the health of the capital

With this in mind, and through the successful delivery of this strategy the following objectives will be achieved:

¹¹ Hirvikoski T. et al. (2016). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 207(5), 232-8.

- Ensure equity of access and care for everyone who needs to and does contact our services
- Support delivery of the Trust values: Respectful, Professional, Innovation and Collaborative.
- Ensure the Trust is compliant with National guidance and requirements
- Improve safe, effective and sustainable emergency healthcare for Autistic people pan London.
- Effective engagement with the autistic community, with outcomes that reflects the aims of and feedback from the Public Patient Council subgroup for autistic people (and people with a learning disability).
- National and London wide priorities for Autism care identified by the NHS England London Autism Strategy are reflected in local Trust strategy.
Liaison with and guidance from the NHS England London Autism Strategy lead will ensure this.

Service actions

<u>Number</u>	<u>Action</u>	<u>By when: Year</u>
1	Equal representation at the Learning Disability and Autism Public patient council of people with a learning disability and autistic people	Year 1
2	When developing training/ education materials for staff this should be undertaken using co-production ensuring autistic people must be individually represented	Year 2
3	Education content is informed by those with lived experience to ensure delivery promotes engagement and effectively benefits Autistic people.	Year 2
4	To review Business Intelligence data and report all deaths determined as appropriate to the online LeDeR system on a monthly basis in line with the national requirement.	Year 1
5	National and local LeDeR recommendations will be monitored to ensure actions are reflected in LAS development plans and service delivery. When the LeDeR national report focusing on the deaths of Autistic people is published, the Learning Disability and Vulnerability Specialist will explore the transference of findings within the ambulance service and integrate recommendations into LAS practice.	Year 1
6	Open communication will be promoted encouraging joint working between the LAS and local LeDeR panels. This will be achieved through attendance at review and strategy meetings and ongoing liaison with the pan London lead for guidance on LeDeR trends and	Year 1

	local priorities across London.	
7	The Learning Disabilities and Vulnerabilities Specialist will attend local LeDeR reviews where feedback from the LAS is requested.	Year 1
8	All patients going through the internal Learning from Deaths pathway identified as being an Autistic person, must be referred to the Learning Disability and Vulnerabilities Specialist for a specialist review	Year 1
9	In line with government and CQC requirements, the LAS will implement Autism statutory/mandatory training for all staff to the appropriate level depending on their job role as outlined in the Core Capabilities Framework when published.	Year 3
10	Continuing Professional Development learning events to be offered on specific topics that reflect the need for additional understanding and learning. These will be identified through LeDeR reviews, learning from death reviews or newly released clinical guidance.	Year 1
11	Internal review of standard process and contingency escalation plans to establish whether these are effective and reasonable to incorporate the needs of autistic people without impacting the outcome of care they receive. Ongoing consideration as new pathways are established across the Trust.	Year 2
12	Open dialogue with external organisations surrounding conveyance and support options in the community for onward pathways of care when conveyance is not the most appropriate option from clinical presentation	Year 3
13	Promotion of the Universal Care Plans for use by and for the Autistic people to improve patient care and planning	Year 1
14	Review of the internal APP-UC care pathway to establish effective uptake and use of this resource including pathway development	Year 1
15	A scoping exercise to be completed to enable understanding of the experiences of autistic people accessing the Trust for see and treat services including: the number of people supported, reasons for contact with the LAS and outcomes of attendance. This exercise should inform Trust direction to focus and inform service delivery with a focus on mental health presentations, alongside liaison with community and inpatient services to improve pathways and liaison between services.	Year 1

Assessment of where we are currently:

Prior to the development of this strategy, the Trust have looked to implement actions that improve our understanding of the service we provide and implement initial actions to engage more meaningfully with Autistic people across London. The Trust continue to implement and work on:

- Leading on the development and implementation of the “Universal Care Plan” across London for Autistic people. Exploring and implementing the use of this established online care plan for Autistic people aims to improve patient care by enabling crews to have relevant information at hand on how to meet a person’s personalised care needs in a timely way.
- Establishing a new internal care pathway
The Advanced Paramedic Practitioner in Urgent Care (APP-UC) programme operates across London. APP-UC clinicians are educated to post-graduate degree level, undertake advanced clinical assessments, and provide additional clinical interventions including wound closure, point of care blood testing and supply medications under Patient Group Directions (PGDs). The APP-UC team screen calls in the Tactical Operations Centre (TOC) and target the dispatch of clinicians to a wide variety of presentations including acute and chronic presentations relating to low acuity or complex conditions.
It has been recognised the important role this team can play using their scope of practice in enabling autistic people to receive appropriate care at home without needing to be conveyed to hospital or another urgent care environment for further assessment. In doing so this reduces multiple barriers autistic people can experience in accessing healthcare in a timely way. A new standard operating procedure, training and internal referral pathway has been established to ensure familiar, quicker and standardised access to this side of the service for autistic people
- An internal campaign called “Ask the question” has focused on how we find out whether a patient is an autistic person. This is the starting point of then ensuring we next consider how we can make any reasonable adjustments, adapt our practice and inform our clinical reasoning.
- The development of a sub group of the LAS current Public Patient Council has enabled the facilitation of a meaningful way to ensure autistic people are engaged and represented to contribute to the Trust.
To promote accessibility across London, two meetings run quarterly in line with the primary Public Patient Council, one virtually and another face to face
- Implementing national statutory/mandatory training.
The Trust has implemented tier 1 e-learning of the Oliver McGowan Mandatory training in Learning Disabilities across the service. At this time we are continuing to engage with the local ICB to discuss the delivery of the virtual element of this training with people with lived experience.

Focused work streams

1. Engaging with Autistic people

Engaging with the population of London incorporates listening to feedback on our service, involving the expertise of those with lived experience in how this is delivered and providing meaningful tailored education. All of these aspects need to be considered when evaluating how the LAS can develop its engagement with the Autistic people within London.

Equal representation at the Learning Disability and Autism Public patient council of people with a learning disability and autistic people

Using accessible ways to collect feedback is important to ensure all voices are heard and everyone has the ability to express opinion on how the LAS may impact them and the care they receive in a meaningful way.

Autistic people are often under represented within patient feedback and surveys which are used to understand patient experience and shape service delivery.

Within the trust one of the ways the understanding of patient satisfaction is contributed to is through collection of data through the “Public Perceptions to the London Ambulance Service” report. Patients who have increased difficulty responding to information over the telephone or requests for information may however have increased difficulty engaging with providing feedback, meaning they are unable to work collaboratively with services and their experiences are not reflected.

The established LAS Public Patient Council in its standing format was not accessible to all autistic people with wide varying support needs to take part in a meaningful way.

A Learning Disability and Autism sub group of the Public Patient Council has been created to enable this to be facilitated and ensure representation, engagement and assurance in the trust. This includes addressing topics decided by the council, informing and approving project work and assurance on the work of the Learning Disability and Vulnerabilities Specialist Having representation across London and from many different organisations or individuals is very important. Priority must be given to ensure the new council is nurtured, maintained and developed as it becomes fully established and attendance is equally distributed and primarily for people with lived experience instead of other experts by experience from whom the Trust can seek feedback and collaboration is alternate forums.

When developing training/ education materials for staff this should be undertaken using co-production ensuring autistic people must be individually represented

Understanding and recognising the individual nature of an autistic person is paramount, without attempting to group an autistic person into another demographic such as mental health or learning disabilities.

It is essential to recognise that working collaboratively with people with lived experience must include autistic people as active and represented participants, people with a learning disability cannot represent autistic people and vice versa.

Education content is informed by those with lived experience to ensure delivery promotes engagement and effectively benefits Autistic people.

A “one size fits all approach” does not work and may serve to disengage people from the education message being delivered.

Autistic people may have specific barriers they experience to accessing the LAS and similarly may not experience barriers that other patient demographics do. Merging educational resources does not encourage engagement with the content and makes it harder to relate to. Listening to what focused education would be beneficial and how this can be delivered from

people with lived experience will help the Trust to deliver meaningful messages to positively influence a person's engagement and confidence in accessing the service. An example of this may be: "What are the sensory demands of going in an ambulance and how can these be reduced."

The service's current delivery of public education doesn't include a focused work stream to identify and deliver focused content for autistic people, covering the range of support or information people may benefit from. This includes community outreach, delivery and college/school education.

Work has been identified to enhance the accessibility and reach of LAS educational messaging to ensure equal access to healthcare when completing face to face education sessions. This includes reflecting on our session outcomes, adapting our delivery and approach by considering communication strategies and personalised reasonable adjustments.

2. Learning from the Deaths of Autistic people

The NHS Long Term Plan¹² (2019) has made an ongoing commitment to supporting and funding the LEDER programme. In turn this is equally reflected in NHS operational planning guidance for 2022/2023¹³, highlighting focus must be given to implementing the actions coming out of Learning Disability Mortality Reviews (LeDeRs) to tackle the inequalities experienced by autistic people and separately people with a learning disability. Learning from the deaths of Autistic people serves to ensure service development and understanding that can prevent future unnecessary deaths due to the right healthcare not being in a timely way.

1. Liaising with the Learning Disabilities Mortality Review Programme (LeDeR)

To review Business Intelligence data and report all deaths determined as appropriate to the online LeDeR system on a monthly basis in line with the national requirement.

National and local LeDeR recommendations will be monitored to ensure actions are reflected in LAS development plans and service delivery. When the LeDeR national report focusing on the deaths of Autistic people is published, the Learning Disability and Vulnerability Specialist will explore the transference of findings within the ambulance service and integrate recommendations into LAS practice.

Open communication will be promoted encouraging joint working between the LAS and local LeDeR panels. This will be achieved through attendance at review and strategy meetings and ongoing liaison with the pan London lead for guidance on LeDeR trends and local priorities across London.

The Learning Disabilities and Vulnerabilities Specialist will attend local LeDeR reviews where feedback from the LAS is requested.

¹² The NHS Long Term Plan. 2019. Accessed on 16/03/2022 at <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>

¹³ NHS England and NHS Improvement. 2021. 2022/23 priorities and operational planning guidance. Accessed on 16/03/2022 at [B1160-2022-23-priorities-and-operational-planning-guidance-v2.pdf \(england.nhs.uk\)](https://www.england.nhs.uk/wp-content/uploads/2022/02/b1160-2022-23-priorities-and-operational-planning-guidance-v2.pdf)

The LeDeR programme produce a yearly policy¹⁴ and national objectives incorporating actions from learning to inform measures organisations across health and social care should put into place to address inequalities and prevent premature deaths. The LeDeR programme included Autistic people within its reporting in September 2022. There is not therefore a yearly report yet that specifically focusing on the needs of Autistic people within healthcare.

Local LeDeR steering groups will also disseminate local learning from patient reviews where identified system failings have contributed to a patient's death. These may or may not include recommendations for the London Ambulance Service however a dynamic approach to sharing cross service learning and reflection should be used to be responsive to identified barriers in healthcare provision. Thus enabling the trust to have a proactive approach to developing and adapting our own service provision to minimise risk, prevent harm and improve the quality of our service.

The nature of the service LAS provides is reflective of only a snapshot of the patients overall contact with healthcare throughout their lives. However during that time the potential for immediate impact on the life and death of the autistic patient or to set into motion a sequence of events that influences ongoing healthcare beyond our service is immeasurable. Recognising this influence beyond our immediate contact, enables us to recognise the essential responsibility we hold when working with patients with a learning disability to access services across healthcare and to learn and collaborate alongside our health partners.

The LAS therefore holds three key responsibilities in line with national policy and guidance:

- i. To stop further preventable deaths of Autistic people by reflecting on and learning from the national and local findings and recommendations made by LeDeR and implement these widely into the service we provide.
- ii. To contribute to the ongoing national learning and support the LeDeR programme by reporting deaths of Autistic people who we recognise as having passed away.
- iii. To use evidence based and clinical best practise reflected through LeDeR guidance, to ensure we are providing the highest level of personalised health care to Autistic people.

2. Learning From Deaths Internal Review Process

All patients going through the internal Learning from Deaths pathway identified as being an Autistic person, must be referred to the Learning Disability and Vulnerabilities Specialist for a specialist review.

In line with the trusts commitment to continuously improve the quality and safety of the care provided by learning from the deaths of patients as set out in the Learning from Deaths Policy, where there is a death of an autistic person, the Learning Disabilities and Vulnerabilities Specialist will be part of this review process. This will enable consideration of best practice guidance when working with autistic people and support identification of learning themes.

Dissemination of learning from these reviews will take place through multiple forums. Learning from incidents is cascaded via the Safeguarding Newsletter, fed into training events and

¹⁴ NHS England and NHS Improvement. 2021. [Learning from lives and deaths – People with a learning disability and autistic people \(LeDeR\) policy 2021](#)

included in full staff updates such as clinical bulletins. The Trust Head of Safeguarding & Prevent is a member of the Serious Incident Review Group and liaises with the Learning Disabilities and Vulnerabilities Specialist to provide support in disseminating learning from incidents involving autistic people.

3. Education and Training

Recognising the varied and unique provision of healthcare within ambulance services as a whole, it is essential the training we provide as a trust to practitioners is focused and inclusive of evidenced based and clinical best practise relevant to the roles and responsibilities of our staff rather than having a generic focus. This will enable best possible care provision and health outcomes for our patients.

The trust vision is to provide high quality, setting focused training to all its staff. Specific context based training is required to change culture and enable staff to provide a high and safe level of care, that is relevant to working within emergency healthcare. This training should draw on evidence based and best practise, national guidance and local learning.

In line with government and CQC requirements, the LAS will implement Autism statutory/mandatory training for all staff to the appropriate level depending on their job role as outlined in the Core Capabilities Framework when published.

Continuing Professional Development learning events to be offered on specific topics that reflect the need for additional understanding and learning. These will be identified through LeDeR reviews, learning from death reviews or newly released clinical guidance.

Echoing LeDeR national guidance, The NHS Long Term Plan states requirements for the NHS to “improve its understanding of the needs of people with learning disabilities and autism, and work together to improve their health and wellbeing”¹⁵.

An amendment to the Health and Social Care Act 2022¹⁶ saw the requirement for all regulated services to provide Learning Disability and Autism training for their staff at the level which is appropriate to the role.

In line with this inclusion, the Care Quality Commission also reflected this change in their Training Regulation 18(2)(a).

It is the Trust’s responsibility to ensure we are compliant with this requirement within law. A Code of Practice involving public consultation is expected to be published in Autumn 2023 to support this training, setting out what must be included within it to meet the legal requirement.

As discussed, the LAS has already implemented the e-learning element of the tier 1 Oliver McGowan Training in Learning Disabilities and Autism and is awaiting guidance from the ICB on how the online interactive session can be rolled out locally.

The Trust is continuing to explore the most effective way to develop the skills and knowledge in providing high quality, timely healthcare to autistic people within the context of the London Ambulance Service for those requiring tier 2 level training.

¹⁵ NHS England and NHS Improvement. 2019. The NHS Long Term Plan: Learning Disability and Autism, Pg 52 [NHS Long Term Plan v1.2 August 2019](#)

¹⁶ [Health and Care Act 2022 \(legislation.gov.uk\)](#)

Staff's current knowledge, skills and experience in meeting the needs of autistic people relevant to their job role can be inconsistent across the trust.

Prior to the requirement for statutory/mandatory training, the Learning Disability and Vulnerability Specialist has been delivering focused training to particular staff teams. Due to reduced capacity to deliver this across the Trust, this training has been directed towards those who provide clinical or managerial supervision/guidance to other members of staff, influencing patient care. This has ensured a top-down approach to ensuring all staff including operational hear and treat and see and treat colleagues are able to access further support and guidance to inform their clinical reasoning and practice when supporting autistic people where appropriate.

The Core Capabilities Framework for Supporting Autistic People¹⁷ outlines key elements training must include based on job role and responsibility which has informed this training content.

4. Pathways of Care

***Internal review of standard process and contingency escalation plans to establish whether these are effective and reasonable to incorporate the needs of autistic people without impacting the outcome of care they receive.
Ongoing consideration as new pathways are established across the Trust.***

During periods of high demand, contingency operations in place can mean patients are asked to contact alternative areas of the service such as 111 for further more in depth assessment. Barriers in accessing services can mean that being asked to re contact another area of the service or being passed between service provisions can lead to reduced service accessibility, timely care and missed presentations of clinical deterioration. It is appropriate therefore to consider whether these clinical pathways are appropriate for autistic people and how service delivery can incorporate reasonable adjustments to prevent autistic people being placed at disadvantage.

Open dialogue with external organisations surrounding conveyance and support options in the community for onward pathways of care when conveyance is not the most appropriate option from clinical presentation

Multiple experiences by Autistic people can impact on whether someone is able to engage with the process of attending hospital when this is medically required. Complex scenarios can arise in this situation when looking for teams and organisations who are able to continue to meet the presenting needs of a patient in a safe and timely way.

The LAS is a 24/7 service however community services and primary healthcare is predominantly available Monday-Friday 9-5. This means that outside these times crews have increased difficulty accessing a clinician or service that knows the patient well or may be able to best meet the patient's presenting need in a timely way. A lack of clear and consistent pathways of care for Autistic people can impact receiving timely healthcare in the most appropriate environment as well as an increase in potential preventable hospital admissions or adverse experiences accessing crisis care, which have a lasting impact on the person's wellbeing and willingness to engage with services

¹⁷ Skills for Health, Health Education England and NHS England. 2019. Core Capabilities Framework for Supporting Autistic People Accessed on 06/06/2023 at <https://www.skillsforhealth.org.uk/wp-content/uploads/2020/11/Autism-Capabilities-Framework-Oct-2019.pdf>

in the future. When a patient has identified healthcare needs however is unable to access hospital, clinicians have access to a range of approved services via the Directory of Services (DoS) (111 IUC and Clinical Hub) and MiDoS (ambulance crews). Knowing the approved or best continued pathway of care to choose to meet a patient's presenting needs particularly outside of standard working hours can be difficult, especially if a full assessment could not be completed.

Working alongside individual ICBs and commissioning groups to establish alternative service provision and accessibility to autistic people is essential. Exploring and trialling alternative care pathways with external organisations would improve both patient care and organisational demand.

Promotion of the Universal Care Plans for use by and for the Autistic people to improve patient care and planning

Historically there has not been an established care planning tool used by Autistic people and accessed by health services to inform personalised care.

This prevents reasonable adjustments being made in a timely way and reduces engagement with services, resulting in poorer health outcomes as a persons individualised support needs have not been met. Similarly a knock on effect of reduced communication between agencies, information sharing and joint up care results in Autistic people receiving un-equal healthcare.

The pan London Universal Care Plan is an online care planning tool which is established across urgent and emergency care.

Ongoing template development provides the capability for care plans to be created which meet the individualised needs of autistic people within an established care plan template.

Promotion of these care plans for completion by autistic people will enable access to personalised information by both urgent and emergency care services, improving patient care pan London through: personalised reasonable adjustments for patients enabling engagement in services, better understanding of a patient's physical health presentation, increased knowledge of communication needs leading to better patient inclusion in decision making and Mental Capacity Assessments and joint working by improving patient handover between emergency and acute care, consistent information sharing between services.

As a primary user of the information within the care plans, the LAS has a significant role in advocating for and promoting the care plans across primary care, advocacy and support services and charities.

Review of the internal APP-UC care pathway to establish effective uptake and use of this resource including pathway development

The Advanced Paramedic Practitioner Urgent Care team aim to “assess, treat and safely discharge patients, or utilise appropriate care pathways to reduce unnecessary hospital admissions.”

Holding an extended scope of practice including enhanced tools for assessments and medication, there is increased opportunity to be able to meet the health needs of

Autistic people at home such as point of care blood tests, and wound closure. The NHS Long Term Plan, reiterated by the 2022/23 Operational Planning Guidance highlights the requirement of services to commit to reducing the reliance on inpatient care and support admission avoidance for autistic people. By developing this new pathway of care and providing hospital interventions in the pre hospital environment, the LAS will create fairer access to healthcare, better meet patient's individual needs by enabling an increased number of patients to remain at home and have their health needs met.

The Learning Disabilities and Vulnerabilities Specialist has worked alongside the Advanced Paramedic Practitioner Urgent Care (APP-UC) team on a joint project to explore how Autistic people may appropriately have their healthcare needs met within the APP profile of work and how a new pathway of care can be set up to execute this.

A review of this project will establish whether this pathway is an effective use of the APP-UC skills set to meet the personalised care needs of autistic people and has met the desired outcome of people receiving care in the right place, at the right time by the right people, in turn reducing hospital admissions and improving patient outcomes. Similarly further understanding on how this pathway can be strengthened from practise based evidence can be undertaken.

5. Autism and mental health

A scoping exercise to be completed to enable understanding of the experiences of autistic people accessing the Trust for see and treat services including: the number of people supported, reasons for contact with the LAS and outcomes of attendance. This exercise should inform Trust direction to focus and inform service delivery with a focus on mental health presentations, alongside liaison with community and inpatient services to improve pathways and liaison between services.

There is an increased prevalence of Autistic people experiencing poor mental health, with anxiety and depression being the most common mental health problems among autistic people. Reasons for these experiences specifically linked to Autistic people may be:

- A sense of being misunderstood and/or not accepted by non-autistic people
- Difficulty identifying, understanding and managing emotions
- Not receiving the right support
- People's experiences of difficult social situations and sensory environments increasing stress
- A change to routine, particularly an unexpected change may create anxiety

Similarly research shows that autistic people are significantly at higher risk of suicide than the general population. ¹⁸ Research has shown suicide is the most prevalent

¹⁸ <https://www.autism.org.uk/advice-and-guidance/topics/mental-health>

reason that Autistic people die 16 years earlier than the general population, followed by epilepsy. These higher rates have been associated with:

- Lower life satisfaction
- Greater social difficulties
- Loneliness

With this recognition there is a national focus on improving mental health services for autistic people. Without effective care pathways and community services in place, autistic people are often met in crisis as there are no other services in place to provide support or the person has not been deemed eligible under the Care Act 2014 as having care and support needs.

It is often therefore in this context that autistic people present to the London Ambulance Service in acute mental health crisis.

Similarly locally anecdotal reporting indicates that autistic people are more likely to be inappropriately referred to the mental health team due to misunderstanding around a person's presentation that is assumed to be an acute mental health presentation however instead has origins in emotional dysregulation, sensory integration or a meltdown/shutdown presentation. All of which can impact a person's presentation, distressed behaviours and communication.

Whilst the London Ambulance Service has a mental health team, the coverage of these responders at any one time across London will mean that there is a significant proportion of the time a double crewed ambulance would also respond to an autistic person in high levels of distress. Service development can therefore use the expertise and service knowledge of the mental health team but should be transferrable and incorporated into standard practice across the trust. This includes but is not limited to the identification and understanding of the difference between a person presenting with in an acute mental health crisis or a person experiencing distressed behaviour relating predominantly to their experience as an autistic person. Understanding distressed behaviour is essential to ensure changes in consideration and the response that people receive both when designing and delivering services. Providing knowledge around sensory integration and sensory based approaches initially to the mental health team, will incorporate alternate ways of understanding distressed behaviours as well as further understanding as to what may impact a person's behavioural and engagement responses both with the Trust as a whole and on scene. This knowledge will allow more personalised care to be delivered, promoting improved health outcomes and service accessibility.

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