



London Ambulance Service NHS Trust

Providing high quality care for patients with a Learning Disability

Trust Strategy 2022-2025

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Date of review: March 2023



Background

There are currently 1.5 million people with a learning disability living in the UK (1.2 million in England)¹, equating to approximately 2.16% of adults and 2.5% of children in the UK.

Mencap² describes a Learning Disability as a reduced intellectual ability which may affect how someone is able to understand new or complex information and difficulty with everyday activities, affecting someone for their whole life. The difficulties a person may experience will vary from person to person however may include elements of difficulty learning new things, understanding complicated information and interacting with other people, processing information and managing day to day activities independently³. Evidence indicates that people with a Learning Disability are also increasingly likely to experience additional physical health conditions and mental health problems.

Research highlights people with a learning disability are four times more likely to die prematurely than the general population, with people with a learning disability dying 16 years earlier (18 years shorter for a woman, 14 years shorter for a man). The difference in the medium age of death when comparing those with and without Learning Disabilities is 23 for men and 27 years for woman (this increases with the severity of Learning Disability a person experiences due to increased multiple comorbidities and in turn increased barriers experienced to access healthcare).

Significantly 38% of the premature deaths of those with Learning Disabilities are from avoidable causes.⁴

Growing out of the Confidential Inquiry into Premature Deaths of People with a Learning Disability (2013), the national Learning from lives and deaths- People with a Learning Disability and Autistic people (LEDER) programme funded by NHS England and NHS Improvement was set up in 2017. As a service improvement programme, by reviewing every life and death of a person with a Learning Disability or Autistic person in England, it produces learning and looks at areas of improvement across health and social care when working with patients with Learning Disabilities or Autistic people. Through this action, the programme looks to improve care, reduce health inequalities and prevent premature death within this patient group.⁵

The NHS Long Term Plan (2019), The Care Act (2014), Valuing People Now (2010), Death by Indifference (2007) and Mental Capacity Act (2005) all highlight the shared need to prioritise standards of care for those with Learning Disabilities including equitable healthcare access, personalised care, communication considerations, service quality safeguards and professional responsibility.

As services across healthcare look to improve the provision of care and equitable service for those with Learning Disabilities in line with these recommendations, continued disadvantage and disparity is recognised and reported throughout health and social care provision.

¹ Office for National Statistics. 2019. Estimates of the population for the UK, England and Wales, Scotland and Northern Ireland

² Mencap (2022) What is a Learning Disability? Accessed 09/02/2022 at <https://www.mencap.org.uk/learning-disability-explained/what-learning-disability>

³ Foundation for People with Learning Disabilities. 2021. Accessed on 09/02/2022 at [Learning disabilities | Foundation for People with Learning Disabilities](#)

⁴ Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. 2013. Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). *Bristol: Norah Fry Research Centre*

⁵ NHS England and NHS Improvement. 2021 Accessed on 09/02/2022 at [Learning from lives and deaths – People with a learning disability and autistic people \(LeDeR\) policy 2021](#)

LeDeR continues to highlight persisting worse physical and mental health for those with Learning Disabilities, outlining in their [2020 annual report](#) the ongoing impact of this resulting in increased premature deaths of those with Learning Disabilities, notably from preventable causes.

The current climate of Covid19 has served to highlight these ongoing health inequalities and on the back of this a culture of change that is required to the processes and systems we use to ensure the health needs of those with Learning Disabilities are recognised and met.

Both the Confidential Inquiry into Premature Deaths of People with a Learning Disability (2013) and LeDeR (2021) have explored the issues that have contributed to the premature deaths of people with a Learning Disability. One of the significant influencing factors indicated is the health inequalities experienced by this patient group.

Recognising the barriers leading to these health inequalities has been an important element of the LeDeR process, to understand what is preventing patients with a Learning Disability receiving the right care at the right time.

Clear barriers experienced by patients with a Learning Disability and leading to health inequalities include⁶:

- Recognising a person has a Learning Disability
- Understanding what it means to have a Learning Disability
- Understanding and making Reasonable Adjustments
- Recognising a person's communication needs
- Understanding and supporting capacity decisions appropriately
- Recognising when someone may be unwell but has an atypical presentation of this eg. pain
- Working jointly with carers and family.
- Lack of appropriate care pathways
- Reduced joint working between agencies

Making the direct link between these barriers and the premature, avoidable deaths of people with a Learning Disability is essential to understanding the severity of not fully exploring and implementing actions to alleviate them within our own service.

Aims and objectives of this Strategy

This strategy explains the vision we have to support patients with a Learning Disability 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 patients with a learning disability 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 patients with a Learning Disability across the capital.

Through the successful delivery of this strategy the following objectives will be achieved:

- Ensure equity of access and care for everyone who needs to and does contact our services

⁶ Mencap. 2021. Access to healthcare. Accessed on 14/02/2021 at [Learning Disability - Health Inequalities Research | Mencap](#)

- Support delivery of the Trust values: Respectful, Professional, Innovation and Collaborative.
- Ensure the Trust is compliant with the Learning Disability Improvement Standards for NHS Trusts⁷
- Improve safe, effective and sustainable emergency healthcare for patients with a Learning Disability pan London.

This strategy explores several key 'Work streams' across the trust against nationally recognised barriers to accessing healthcare and Learning Disability best practise. These are:

1. Urgent Care/111
2. Engaging with the Learning Disability Community
3. Learning from the Deaths of patients with a Learning Disability
4. Education and Training
5. Pathways of Care
6. Creating Accessible Environments

Scope of policy:

To inform this strategy, a scoping exercise was completed by the Learning Disability and Vulnerability Specialist. This has involved visiting different areas across the trust, completing observations of practise, meeting with staff members and reviewing patient contacts and incidents. Similarly a benchmarking exercise took place to understand the current service delivery against the Learning Disability Improvement Standards for NHS Trusts (2018)⁸.

Stakeholder feedback has been sought through varied forums to inform our knowledge of the patient experience and agencies which support them. An external Stakeholder Forum- "Providing Urgent and Emergency Care for patients with Learning Disabilities" has taken place and received pan London representation from community specialist learning disability health and social care teams, supported accommodation staff, learning disability commissioning leads, GP leads, community, acute learning disability liaison nurses and the LAS Public and Patients Council. Identification of themes from the feedback we received and discussions that took place has been completed (see Appendix 1).

These themes, alongside the scoping exercise and implementation of clinical best practise when providing healthcare to patients with a learning disability, have been used to inform the exploration of each work stream presented and service actions.

It is important to note there is 2 further stakeholder events planned - one for patients and their family carers and the other for the wider staff body across the trust. The completion of these has been prevented so far due to the ongoing risk of COVID19 impacting on in person meetings particularly for those who may be clinically vulnerable and the effect of COVID19 on service pressures, influencing the ability for staff to engage meaningfully in this kind of event. Once completed, evaluation from these events will be fed into the trust understanding and actions going forward.

⁷ NHS Improvement 2018. Learning Disability Improvement Standards for NHS Trusts
[v1.17-Improvement-Standards-added-note.pdf \(england.nhs.uk\)](https://www.england.nhs.uk/wp-content/uploads/2020/08/v1.17-Improvement-Standards-added-note.pdf)

⁸ NHS Improvement. 2018. Learning Disability Improvement Standards for NHS Trusts. Accessed on 16/03/2022 at
<https://www.england.nhs.uk/wp-content/uploads/2020/08/v1.17-Improvement-Standards-added-note.pdf>

Evaluation of 'Work streams' across the trust against nationally recognised barriers to accessing healthcare and Learning Disability best practise.

1. Urgent Care/ 111 Service

Overarching aims of the service:

For patient's to gain advice on presenting health needs that may require urgent attention, where they are unable access their GP service. Urgent care services support to identify the correct care pathway for patient's accessing the service. In doing so, where possible reducing the number of ambulance attendances and conveyance to hospital.

Current context:

- The importance of patients with a learning disability receiving timely focused care by the right agency is paramount to positive health outcomes. With poorer outcomes and experience identified when attending acute/inpatient healthcare (Louch et al, 2021)⁹, the role of urgent care has the potential to align significantly with promoting better health outcomes for patients with a learning disability.
- National patient experience data is collected and outlined in "[Integrated Urgent Care / NHS 111 Patient Experience Survey, England October 2020 to March 2021](#)". Those who have increased difficulty with accessing technology and responding to information in this format may have increased difficulty engaging with this method of data collection and so typically we will not see their views and experience represented in the sample collected. It is often for similar reasons, the same patients will have difficulty accessing and engaging with our 111/ Urgent Care Service.
It is therefore important we recognise the potential for selection bias within this report and explore further the experiences of those with a Learning Disability when accessing our service.
- Learning disability mortality review (LeDeR): Action from learning report 2020/21, highlight's focused learning and development required for urgent care services within their ongoing recommendations "Recommendations from the 2020 University of Bristol LeDeR report and our proposed actions in response to them":

⁹ Louch G, Albutt A, Harlow-Trigg J, Moore S, Smyth K, Ramsey L, O'Hara JK (2021) Exploring patient safety outcomes for people with learning disabilities in acute hospital settings: a scoping review. *BMJ Open*. Accessed on 14/02/2021 at <https://dx.doi.org/10.1136%2Fbmjopen-2020-047102>

No.	University of Bristol recommendation	Audience	Proposed action by NHS England and NHS Improvement
7.	Commissioning guidance for NHS 111 services to include a requirement for the provision of specifically tailored training to NHS 111 staff about how to respond appropriately to calls about people with a learning disability or from people with a learning disability and their families.	NHS England and NHS Improvement	<p>We are working to improve the quality of 111 services offered to people with a learning disability and autistic people.</p> <p>We will include appropriate training for NHS 111/integrated urgent care staff on how to respond to calls from or about people with a learning disability, as a requirement in the national integrated urgent care service specification for NHS 111 commissioners to implement via their individual contracts. This will include training on the provision of reasonable adjustments.</p>

Where can we recognise barriers to achieving these service aims for patients with a Learning Disability?

External stakeholder feedback described barriers for patients with a Learning Disability accessing urgent care/111 services.

Combining both stakeholder feedback and information from the scoping exercise, the following barriers have been identified when exploring the service provision for those with a Learning Disability:

- Urgent Care and 111 is predominantly telephone based which naturally creates a significant barrier for those who have difficulty with verbal and nonverbal communication. Adapting the communication we use when assessing someone on the phone with a learning disability is essential to enable engagement in the process.
- Patients with a learning disability can sometimes feel rushed when using the service. This may be due to service demand particularly during Covid 19 and the completion of assessment through a national standardised system however can impact on a person's impacting understanding, communication and engagement between the person delivering care and patient.
- Health support is initially delivered through the completion of a national generic system to ensure standardised, measureable care for all. This however presents a barrier in meeting the personalised needs of people with a learning disability and recognising individualised presentations.
- Patients with an 'Urgent Care Plan' (who may therefore have a Learning Disability) are placed in a queue for (priority 2) clinician call back. This is implemented to complete a more in depth assessment, recognising the increased potential complexity of the presenting need due to a care plan being in place. Waiting to be called back can be confusing and distressing due to the uncertainty and anxiety this creates.
- Patients and their support networks have reported feeling uncertain about what questions will be asked when calling the service. This can lead to increased anxiety in using 111 and uncertainty that in doing so the right help will be received.

¹⁰ NHS England. 2021. [LeDeR-Action-from-learning-report-202021.pdf \(england.nhs.uk\)](#) page 58

- Following the national Pathways system does not currently provide an option for Health Advisors to identify whether the caller has an additional support needs that may impact on the support they need throughout the call. Not knowing what a person's potential support needs are creates a barrier in being able to make reasonable adjustments for the patient on the phone, as well as potentially influencing clinical decision making during assessment if passed for further clinical assessment.
- Health advisors newly receive training as part of a wider generic training package highlighting considerations when supporting a person with a Learning Disability as part of their induction. Currently this is not expanded within the internal training provided for current health advisors in position prior to this addition or is inclusive of an ambulance service focus. It is extremely important for all Health Advisors to have increased awareness and knowledge to understand a person's potential needs relating to their Learning Disability, moderate their own communication and understand someone else's.
- Clinicians working within the Urgent Care Service have different professional backgrounds and experience. Based on this previous experience, clinician's may therefore have different skills when working with patients who have a learning disability or thresholds of care which impact the clinical advice given both to patients and crews they support.
- There is ongoing increased use of electronic personalised care plans (The Urgent Care Plan) within the community by those with a Learning Disability. This is a great step forward in enabling personalised care within our service. This does mean however that due to the requirement for patients calling the service with a personalised care plan to be assessed by a clinician, there may be a greater demand placed on clinicians. This has the potential to increase call back times for patients with a learning disability and therefore needs to be considered going forwards as to how this can best be managed to reduce risk and prevent extended wait times.
- Reduced engagement through the 111 service can create barriers for the service in working collaboratively with other health and social care agencies to reduce risk and protect potentially vulnerable patients for example through identification of safeguarding requirements.

Service Actions:

- Development of a service IUC/111 working party, covering all delivery sites and including staff within different job roles to provide a holistic overview and approach. The working party will explore the identified barriers for patients with a Learning Disability accessing the service and the best way to increase skills, knowledge, experience and confidence when meeting the needs of this patient group.
- Training focused on meeting the needs of patients with a Learning Disability to be brought into the Integrated Urgent Care Core Skills Refresher for clinicians to create equitable service delivery, standardised thresholds of care in line with clinical best practise.
- Learning Disability training for Clinical Team Navigators to be explored as a priority around soft signs of deterioration, reasonable adjustments and assessing mental capacity for a patient with Learning Disabilities or an Autistic Person.

- Creation of easy read guidance documents alongside the Public Education team and experts by experience (see Public Education work stream).
- Addition of Learning Disability awareness into the health advisor induction and Pathways update training. This is with the aim of: Increasing the ability to understand a person's potential needs relating to their Learning Disability, moderate communication and understand someone else's to ensure we are correctly gathering information to best meet the person's need.
- To work alongside and input into requests for changes to the pan London Pathways template. This would be to meet the need for health advisors to adapt their communication by for example providing alternative prompts and rewording of questions to enable them to do so whilst still following the pathway of care presented.
- Provide a program of continuing professional development opportunities for staff throughout the year.

2. Engaging with the Learning Disability Community

Overarching Service Aim:

The ambulance service serves aims to connect with the community pan London to teach and share essential information about what to do in an emergency and how to contact the service for help. This can be through community visits, resource packs and collaborative projects.

Where can we recognise barriers to achieving these service aims for patients with a Learning Disability?

- It is recognised that people with a learning disability are more likely to experience social deprivation and exclusion¹¹, influencing the potential for socioeconomic and environmental factors to reduce access to mainstream educational media. As a result people with a Learning Disability may be excluded from receiving community level awareness about how to use and contact the ambulance service.
- Public and community facing education may not be accessible to everyone, particularly if a person benefits from using accessible resources or different types of nonverbal communication. People with a learning disability may therefore find it difficult to be able to fully engage with all work of the Public Education team.

One of the themes emerging from stakeholder feedback has highlighted concerns for people with a learning disability around:

- When to contact the right type of help eg. 999 or 111
- Anxiety caused by not knowing what to expect if attended by an ambulance
- Worry about what will be asked if calling the service and being able to respond appropriately

¹¹ Scior K. Werner S. (2015) Changing attitudes to learning disability. A review of the evidence. Mencap. Accessed on 13/03/2022 at [Attitudes_Changing_Report.pdf \(mencap.org.uk\)](https://www.mencap.org.uk/Attitudes_Changing_Report.pdf)

to get the right help.

Without support to access public education information and messaging, this may impact a person's ability to understand the role of the service and access the necessary emergency or urgent care in a timely way.

- 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 with accessing technology and responding to information over the telephone 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 service's current delivery of public education doesn't include focused Work has been identified to enhance the accessibility and reach of our important 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.
- NHS operational planning 2022/2023 states the requirements for trusts to support national LeDeR objectives in their service delivery. LeDeR has publicised its support for the use of [Restore 2](#)¹², a programme aimed at enabling those supporting and advocating for patients with a Learning Disability around their health needs. The LAS recognises that working alongside a person's support network is crucial. With standardised information also required through national frameworks, when contacting the LAS carers can have difficulty in knowing the best way to advocate and the information to provide relating to a person's personalised support needs or presentation.

Service Actions:

1. The trust to create a learning disability engagement forum made up of experts by experience. This is to work alongside the trust to provide advice, consultation, consistent feedback and accountability to the trusts completion of the Learning Disability Strategy and actions.
2. The Learning Disability and Vulnerabilities Specialist will build on current stakeholder forums by holding an annual event to gather feedback on how the LAS are specifically meeting the needs of patients with a learning disability.
3. Completion of collaborative project between Learning Disabilities and Vulnerabilities Specialist and Public Education to work on:
 - Demystifying the ambulance service
 - Reducing anxiety about contacting and using the service for patients with a learning disability
 - Producing easy read and alternative digital resources for patients with a learning disability to cover important education messages such as: how to contact 999, what to expect when calling 111 and what may happen when an ambulance comes to see you.

¹² NHS England and NHS Improvement. 2021. Learning Disability Mortality Review (LeDeR) Programme Actions from learning: deaths of people with a learning disability from Covid19. Accessed on 14/02/22 at [LeDeR-Action-from-learning-report-202021.pdf \(england.nhs.uk\)](#)

- Supporting the LEDER objective around increased use of Restore 2 in supported environments by providing guidance for support networks on what will be required when they call the service and the most effective ways to advocate for those they support.
 - Increasing the number of community engagement and education opportunities for patients with a learning disability, in an accessible format for pre-planned and open events.
4. Review of key patient facing documents to recognise how these can be developed into easy read resources for inclusion on LAS external website.

3. Learning from the Deaths of patients with a Learning Disability

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

Recognising the essential work required to bring Learning Disability care in line with that experienced by the rest of the population, The [NHS Long Term Plan](#)¹³ (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 2022/2023](#)¹⁴, highlighting focus must be given to implementing the actions coming out of Learning Disability Mortality Reviews (LeDeRs) to tackle the inequalities experienced by people with a learning disability.

The LeDeR programme produce a yearly policy¹⁵ 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 the premature deaths of patients with a Learning Disability and/or Autism.

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 patient with a learning disability or to set into motion a sequin 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.

¹³ 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>

¹⁴ 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 \(england.nhs.uk\)](#)

¹⁵ NHS England and NHS Improvement. 2021. [Learning from lives and deaths – People with a learning disability and autistic people \(LeDeR\) policy 2021](#)

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

- i. To stop further preventable deaths of patients with Learning Disabilities 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 patients with a learning disability (and/or Autism) 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 patients with a learning disability.

2. Contribution to Patient Safety Incident Investigations (PSIIs)

The national patient safety investigation response framework (PSIRF) (of which LAS has been an early adopter site) is focused on improving healthcare systems. By conducting an investigation to identify systematic factors that may have led to the incident, they aim to identify new opportunities for learning that will lead to sustainable, effective change and improvement across services.¹⁶

Recognising specific groups of the population who may be at potentially increased risk of oversight within the healthcare system, key priority patient groups who fall into the PSII criteria have been identified within this framework. 'Death of a person with a Learning Disability' sits within the nationally-defined priorities to be referred for PSII or review by another team and nationally-defined incidents requiring local PSII. This indicates all deaths should be referred to the LeDeR process (as noted above) whilst equally where there is reason to believe that the death may have been contributed to by a problem in the healthcare provided by the LAS, an internal investigation should also be completed.

3. Learning From Deaths Internal Review Process

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 a person with a learning disability the Learning Disabilities and Vulnerabilities Specialist will be part of this review process. This will enable consideration of best practice guidance when working with patients with a learning disability 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 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 patients with a learning disability.

Service Actions:

- The LAS will 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

¹⁶ NHS England and NHS Improvement. 2020. National standards for patient safety investigation Guiding principles and standards for a local, systems approach to patient safety investigation in NHS-funded care. Accessed on 14/02/2021 at https://www.england.nhs.uk/wp-content/uploads/2020/08/Standards_for_PSI_Investigation.pdf

requirement.

- 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.
- National and local LeDeR recommendations will be monitored to ensure actions are reflected in LAS development plans and service delivery.
- The Learning Disabilities and Vulnerabilities specialist will be part of the initial decision to identify whether a referred incident involving a patient with a Learning Disability (or Autism) meets the local criteria for a PSII. Following this if a PSII is to be completed, the Learning Disability specialist should contribute to the investigation and system improvement plan.
- All patients going through the internal Learning from Deaths pathway identified as having a Learning Disability (or Autism), must be referred to the Learning Disability and Vulnerabilities Specialist for a specialist review.

4. Education and Training

Background:

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”¹⁷.

The [Core Capabilities Framework for Supporting People with a Learning Disability](#)¹⁸ outlines key elements training must include based on job role and responsibility when supporting those with Learning Disabilities.

These capabilities are integrated into the proposed national Oliver McGowan Learning Disability and/or Autism awareness training. This training is following the premature death of Oliver McGowan, who on a review of his life and death, found that his death was avoidable and influenced by a lack of understanding by health professionals on how to meet Oliver’s needs relating to his diagnosis of Autism. Outlined in the “[Right to be Heard](#)”¹⁹ consultation, this training is due to be mandated by amending “the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 to require all

¹⁷ 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](#)

¹⁸ Skills for Health, Health Education England and NHS England. 2019. Core Capabilities Framework for Supporting People with a Learning Disability Accessed on 14/02/2022 at [Learning-Disability-Framework-Oct-2019.pdf \(skillsforhealth.org.uk\)](#)

¹⁹ Department of Health and Social Care. 2019. ‘Right to be heard’: The Government’s response to the consultation on learning disability and autism training for health and care staff. Accessed on 16/03/2022 at [‘Right to be heard’: The Government’s response to the consultation on learning disability and autism training for health and care staff \(publishing.service.gov.uk\)](#)

NHS and social care providers who carry out regulated activities to ensure that their staff have achieved the learning outcomes relevant to their role.”

Current provision:

- On joining the LAS, all staff receive training in Equality and Diversity recognising the requirement to treat everyone with dignity and respect and consider their individual needs.
- Staff’s knowledge, skills and experience in meeting the needs of patients with learning disabilities relevant to their job role can be inconsistent across the trust and this has the potential to influence day to day decision making.
- After appointment in May 2021, the Learning Disabilities and Vulnerabilities Specialist now holds responsibility to stay informed of and integrate both relevant emerging evidence based practise and national and local LeDeR learning into service provision and learning opportunities across the trust.
- 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.
- Crews and staff within urgent care have varied options to access a hierarchy of clinical support and enable decision making when presented with a complex scenario or a patient with which they want to ensure they are providing the best patient care.
It is essential therefore that those in the position of providing this clinical advice to their colleagues have the required and highest level of skills to complete their role.
Currently staff within these positions do not receive any additional training on meeting the potential complex clinical health and learning disability related support needs of this patient group to provide crews with further guidance and support. Identifying this should promote the use of a layered system to plan the roll out of such training.
- Within the Emergency Operations Centre, call handlers currently do not receive any learning disability focused training as part of their induction. This impacts on staff ability to have awareness and the experience to understand a person’s potential needs relating to their learning disability, moderate their own communication and understand someone else’s.

Service Actions:

- When the national decision has been made, the trust will support and implement statutory/mandatory training for all staff to the appropriate level depending on their job roles (Tier 1/ Tier 2) outlined in the Core Capabilities Framework.

The trust vision is to provide high quality, setting focused training to all its staff. Specific context based training that is required to enable staff to provide a high and safe level of care, that is relevant to working within emergency healthcare but is not delivered within the Oliver McGowan mandatory training, will be explored within the trust for how this can be incorporated in other training pathways. Key focuses of this may be: Soft signs of deterioration, making reasonable adjustments, communication, assessing mental capacity.

- Once implemented, ongoing 6 monthly review of the trust Learning Disability training package to be completed to ensure this is up to date.
- Meeting the needs of patients with a learning disability to be included in the induction training of new clinical staff who hold responsibility of supporting others with clinical responsibility. Exploration to take place as to how this can be delivered safely and effectively to all current staff with the same levels of responsibility to provide clinical advice and guidance to others.
- Learning Disability awareness training to be added into the call handler's induction and update training. This is with the aim of: Reducing risk and barriers to accessing the service by increasing the ability to recognise a person's potential needs relating to their Learning Disability, moderate communication and understand someone else's to ensure we correctly gathering information to best meet the person's need.
- CPD learning events to be offered on specific topics that reflect the need for additional understanding and learning, identified through LEDER reviews, learning from death reviews or upcoming clinical guidance.

5. Pathways of Care

Background:

- A lack of clear and consistent pathways of care for patients with a Learning Disability has been identified as a significant barrier to patients receiving timely healthcare in the most appropriate environment.
- Multiple influences experienced by patients with a Learning Disability 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.

Current barriers impacting on pathways of care for patients with a Learning Disability?

- 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.
- Covid19 has nationally increased the demand on health service's ability to meet patient's needs in a timely way. This has a sequential impact on ambulance crew's ability to access support in the community in a timely way for patients who require intervention but have difficulty accessing hospital.
- 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.

- It is not in the ambulance crew's scope of practise to be able to complete all assessments that may support to identify the underlying health difficulties for patients with additional needs outside of hospital. This results in patients who find the hospital and ambulance environment challenging, potentially needing to attend hospital for further assessment as this cannot be completed in the community. Alternatively an unmet health need may be created if this is not possible and the assessment cannot be completed by another service..
- Historically there has been a number of care planning tools initiated by different organisations to capture the care and support needs patients with a Learning Disability may experience. Whilst significantly improving service provision and personalised care, these have been created with varying focus, distribution and use across services. This has resulted in an inconsistent, unfamiliar picture of urgent care planning across acute, emergency and community care pan London for patients with a Learning Disability. This has the risk of creating silo working with pockets of information about the best ways to support patients, reducing communication between agencies, information sharing and joint up care.

Service Actions:

- The Learning Disabilities and Vulnerabilities Specialist will work alongside the Advanced Paramedic Practitioner Urgent Care (APP-UC) team on a joint project to explore how patients with a Learning Disability 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.

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 extensive comorbidities that may impact on the health needs of those with a Learning Disability 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 patients with a learning disability. 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.

- Learning Disability focused training will be provided within the APP-UC training programme to provide detailed skills and knowledge in line with this new role.
- Development and use of Pan London Urgent Care Planning Tool for patients with a Learning Disability.

A unique opportunity is presented through the change in commissioning from the Coordinate My Care care planning tool to the new 'Urgent Care Plan' starting April 2022. The new Urgent Care Plan provision enables template development with the capability to create and edit care plan templates, supporting a variety of clinical pathways.

The LAS will support the creation of a new template aimed at meeting the personalised health and support needs of patients with a Learning Disability when accessing primary, urgent, emergency and hospital care to be included within the Urgent Care Plan.

Contributing to this template will improve joint working and multi-agency communication, reduce barriers leading to healthcare inequalities for this patient group and improve patient care pan London.

More specifically it is envisaged the impact will be: improved patient handover between emergency and acute care, consistent information sharing between services, personalised reasonable adjustments for patients enabling engagement in services, better understanding of a patient's physical health presentation and the impact of their learning disability on function, increased knowledge of communication needs leading to better patient inclusion in decision making and Mental Capacity Assessments.

6. Creating Accessible Environments

Background:

- Those with a Learning Disability (and Autistic People) are more likely to experience sensory integration difficulties²⁰. This can make the ambulance experience extremely challenging and distressing given the increase in unknown sensory stimuli being provided eg. Noise/lights/enclosed space/unknown textures/touch of equipment.
- The increase in this sensory stimuli may present such challenge the patient looks to avoid it completely by declining to access the ambulance or demonstrating their experience of discomfort in other ways. Eg. Changes in communication, agitation or behaviour. This therefore may result in the patient not accessing the healthcare they need, increased stress/anxiety or preventing engagement with healthcare provision both with ambulance crew or when arriving at hospital.
- Accessing an ambulance is likely an experience associated with anxiety or distress. There is likely to be increased prevalence and impact of this if a patient experiences benefits from increased support with; communication, understanding abstract concepts and transitioning between unfamiliar environments. This again has the potential to increase the barriers to accessing healthcare for this patient group and facilitate negative associated outcomes.

²⁰ National Autistic Society. 2021. What is autism? Accessed on 16/03/2022 at <https://www.autism.org.uk/advice-and-guidance/what-is-autism>

- During the “Providing Urgent and Emergency Care for patients with Learning Disabilities” external stakeholder event, meeting the sensory needs of patients with a Learning Disability was an area that delegates felt could be explored, acknowledged and improved by the service.
- The Frequent Caller Team provides active input with a small but consistent and significant proportion of patients with a Learning Disability. Within this role the team will have regular contact with the patient’s support networks and patient themselves to raise concern, advice on the role of the ambulance service and proactively address the individual needs of the patient to achieve positive outcomes for both them and the LAS. This may be achieved by developing ‘individual dispatch protocols’, setting up case conferences and working with the patient alongside community healthcare organisations.

It is essential all corporate services providing patient support including the Frequent Caller and Patient Experience teams, maintain up to date skills and knowledge to inform their practice when working with patients with a Learning Disability who may come in to contact with the service.

Service Actions:

- Implementation of a pilot project introducing the use of “Reasonable Adjustment Boxes” onto a select group of new ambulances within the trust.
The purpose of the boxes is for crews to support patients with a Learning Disability (and Autistic people however this sits outside of this strategy) during conveyance to hospital.

The reasonable adjustment boxes will include resources such as noise reducing headphones to support in minimising barriers those with additional support needs including Learning Disabilities have in accessing the ambulance and further healthcare required. They also aim to significantly improve the patient experience, having a direct impact on reducing patient distress and anxiety and consequently leading to better health outcomes by promoting the opportunity for the patient to be more able to engage with the ambulance environment and treatment provision.

Evaluation of impact and outcomes analysis will take place before consideration of next steps and potential for ongoing roll out.

- The Learning Disabilities and Vulnerabilities Specialist post will work alongside corporate services providing patient support to provide role specific Learning Disability training, develop resources used within their pathways and framework to ensure there are easy read options and accessible ways of delivering information to patients.
- The Learning Disabilities and Vulnerabilities Specialist will collaborate with the Frequent Caller Team and local LeDeR leads to explore how communication pathways can be developed to reflect the work of the Frequent Caller Team as appropriate within local reviews.

Trust approval received: 27/04/2022

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