

Dr Karen Henderson
HM Assistant Coroner for Surrey
HM Coroner's Court
Station Approach
Woking
GU22 7AP

7 July 2025

Dear Dr Henderson,

Thank you for conducting a thorough and detailed review of the care provided to Rose Harfleet at the inquest which concluded on the 5th March 2025. I would like to once again take the opportunity to extend our sympathy and condolences to Rose's family and friends and to again apologise for the failings in Rose's care that were identified during the inquest. I welcome the opportunity to address the concerns which you have raised in your Prevention of Future Deaths report issued on the 13th May 2025.

In response to the concerns raised in the Prevention of Future Deaths Report:

1. The management of children with profound disabilities within a hospital setting

Much of the national guidance refers to 'people' and is often based on reviews/studies related to adults with Learning Disabilities. Guidance which specifically addresses the management of children with profound disabilities within a hospital setting is limited and drawn from a number of other associated documents.

The Trust has a Learning Disabilities and/or Autism Policy to Support Children and Adults with Learning Disability and/or Autism. This has been developed in accordance with other national and local guidelines, including the Mental Capacity Act 2005, Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy (2021), NICE NG93 mental capacity, reasonable adjustments and quiet areas, NG11 restraint, Autism Spectrum Disorder in Adults; Diagnosis and Management – Clinical Guide CG142 (NICE 2016), NHSE LD&A Programme 2025 Digital flagging and hospital passports and the Equality Act (2010). Specifically the Trust policy includes an emergency admission flow chart and information about supporting carers and engaging with them in decision making including care and interventions.

As part of our commitment to engage in person centred care, the Trust also engages with the national Learning Disability Improvement Standards Programme, led by NHS England. The latest annual benchmarking exercise was undertaken in 2024-25 which assessed the Trust's performance across four areas, namely respecting and protecting rights, inclusion and engagement, workforce development and specialist care and support. This exercise has identified key areas of progress, as well as priority areas for development over the next year.



There are educational resources available nationally relating to Learning Disabilities and Autism (LD&A). Locally the Trust has a number of resources available for staff which supports staff awareness of both adults and children accessing services with a Learning Disability. This includes information about the following:

- The Learning Disability & Autism Championship Network – the Trust has champions across many areas, including the Paediatric and Adult Emergency Departments, and Hascombe Childrens Ward. The Champions receive specific training 6 times a year from the Learning Disability and Autism Team within the hospital. In total there are currently 49 champions in the Trust.
- Easy read leaflets titled 'Going to Hospital' for children in the Emergency Department and 'Where does it hurt?' picture communication card.
- A pictorial 'Hospital Communication Book' which is available on all wards, and within the Emergency Department and is downloadable from the Trust intranet.
- Posters have been developed for Adult and Paediatric ED waiting areas to ask patients to let us know on check in if they have a neurodiversity.
- Our digital patient record flag system provides early notification of children presenting to the Trust with a Learning Disability.

There is also a specific national mandatory training package that addresses the needs of patients with LD&A called the Oliver McGowan Training.

The Trust began its collaboration with Surrey Heartlands Integrated Care Board in 2023 to support the implementation of Oliver McGowan Mandatory Training on Learning Disabilities and Autism across Surrey. This standardised training is required for all staff, with completion of either Tier 1 or Tier 2 depending on their role within the Trust.

The first stage of both tiers consists of an eLearning module, accessible via the Trust's My Learning portal, and this is mandatory for all staff, regardless of their clinical or non-clinical role. Tier 2 training then progresses to either a full-day face-to-face session or a one-hour interactive online training, both of which are delivered by experts by experience. This training is provided by an external organisation approved by Surrey Heartlands Integrated Care Board and remains available to all Trust staff via the My Learning portal. Availability of face-to-face training is restricted to 30 candidates per session in order to support the wellbeing of the training team, some of whom have lived experience of Learning Disability and Autism. The Trust has procured training sessions to support roll out across the Trust over the next year.

The full implementation of the training program is in its final phase, introducing the one-hour online interactive session, which has recently been made available through the training provider. Completion rates are monitored by the Deputy Director of Nursing and the Adult Learning Disability and Autism Clinical Nurse Specialist. Training is actively promoted through internal communication channels, including staff bulletins, posters, and internal networks. 89% of our Paediatric staff have completed, or are booked to complete, the face-to-face training, the remaining 11% have recently started in post and have completed their on-line training and are awaiting their face-to-face training. In the Emergency Department 100% of Paediatric nursing staff have completed their on-line training and are awaiting their face-to-face training.

In addition to this mandatory training, we continue to provide Trust-specific training, integrating it into staff clinical induction program. The Trust Learning Disability and Autism Team also provide Learning Disabilities and Autism awareness training to new starters to the Trust, Foundation Year 1 and Foundation Year 2 Doctors, International Nurses, and as part of the Health Care Assistant Care Certificate Course. Bespoke training is also provided across the Trust tailored to the specific needs of departments delivering care.

The Trust has also reviewed the Royal College of Emergency Medicine's (RCEM) Learning Disabilities Toolkit, published in September 2024 which promotes specific education and training for Emergency Department staff.

2. Guidelines - consultation with parents and guardians of children with profound disabilities within a hospital setting

The Oliver McGowan training and the RCEM Learning Disabilities Toolkit both promote the importance of engaging with, and listening to, the family or other carers of patients with LD&A and this guidance is equally relevant to all patients with profound disabilities of whatever cause.

Several of the nationally available paediatric early warning scores designed to detect the deteriorating patient and trigger additional clinical review also contain a parameter for staff and / or family / carer concerns.

The Trust is not however aware of any specific national guidance on consultation with the parents and carers of children with profound disabilities although the Trust recognises that this is an essential part of good clinical practice. Whilst not specifically related to children with profound disabilities, the Trust is aware of Martha's Rule, and have been selected to be part of Phase 2 for implementing this. Work has commenced to address the three metrics for delivery for adults and children.

- Patients will be asked, at least daily, about how they are feeling, and if they are getting better or worse. This information will be acted on in a structured way.
- This escalation route will also always be available to patients themselves, their families and carers, and advertised across the hospital.
- All staff will be able, at any time, to ask for a review from a different team if they are concerned that a patient is deteriorating and their concerns are not being responded to.

3. Nursing and Medical care on the ward

The Trust recognises that the care provided to Rose both in the Emergency Department and following admission to our Paediatric ward did not meet the high standards that we would expect and that communication with Rose's mother was inadequate. As documented in the response to question 2 above the importance of communicating with, and listening to, the patient's family and carers is embedded within the Oliver McGowan Training, the RCEM Learning Disabilities Toolkit and the national paediatric early warning scores.

All clinical staff receive mandatory Oliver McGowan training and appropriate training for staff in the use of early warnings scores. In addition to this all Paediatric nurses completed training in confident discussions and raising concerns, pain management, Patient Early Warning Score (PEWS), escalations of care and completed simulation training. 7 overseas nurses have also completed the Evelina Hospital Principles of Paediatric Nursing Training Course.

4. LeDeR Role

The Trust Adult Learning Disability Liaison service is provided by Surrey and Borders Partnership who are commissioned by Surrey Heartlands Integrated Care Board to provide 1 whole time equivalent (wte) band 7 and 0.8wte band 6 Adult Learning Disability nurses. This service supports patients with a Learning Disability who are registered with a Surrey Heartlands GP who are aged 18 and over. There is no commissioned service for a paediatric Learning Disability and Autism nurse.

In addition, the Royal Surrey Foundation Trust funds 1 wte Adult Clinical Nurse Specialist (CNS) and 1 wte Children & Young People's CNS. They provide support to patients with Learning Disability as well as autistic patients. They can provide support to patients from any geographical area. This provision is unique to the Royal Surrey, in that we are the only Trust within our ICB with a designated Children and Young People's (CYP) Learning Disability and Autism Clinical Nurse Specialist.

The CYP Learning Disabilities and Autism Nurse Specialist works Monday – Friday, 08:00 – 16:00. Rose arrived in the Emergency Department on Monday 29TH January and an initial assessment was undertaken at 13:14. Rose was then clerked by an Emergency Doctor at 16:27. Very sadly, Rose passed away before the CYP Learning Disability Nurse returned on Tuesday 30th January, when the CYP Learning Disability Nurse provided support to Rose's family. There was potentially an opportunity for the CYP Learning Disability Nurse to have been contacted by the Emergency Department team following Rose's arrival at 13.14 and prior to the clerking by the Emergency Doctor. The Emergency Department team have been reminded of the presence of the Learning Disability Nurse during working hours and that they can be contacted to help support staff, patients and their families.

The Trust is also aware of the National Confidential Enquiry into Patient Outcome and Death (NCEPOD). NCEPOD is currently conducting a study on acute illness in individuals with a Learning Disability, commissioned by Healthcare Quality Improvement Partnership (HQIP). The aim is to identify avoidable and modifiable factors in the care of patients with a learning disability who are admitted to hospital in a critical condition. This is mainly related to adults with a Learning Disability.

RSFT's Learning Disability and Autism Clinical Nurse Specialist for adults, an intensive care consultant, and the sepsis lead nurse have all been selected as reviewers for this study and are actively participating in case evaluations. During a recent review meeting, the Learning D&A nurse proposed Quality Improvement projects, including the development of a Learning Disability Admission Checklist at RSFT. This checklist will provide key prompts for staff when admitting patients to Emergency Departments and establish a system to record reasonable adjustments that help ensure equitable access to Trust services. The Trust is taking this initiative forward in Quarter 3, 2025.

Thank you for the opportunity to respond to your concerns and I hope that the information contained within this letter is useful. Royal Surrey Foundation Trust will continue to promote education and training addressing the care of patients with profound disabilities and will take forward quality improvement work such as the Learning Disability Checklist mentioned.

Yours sincerely,

[Redacted Signature]

[Redacted Name]

Group Chief Executive