

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

23 June 2025

Our reference: [REDACTED]

Dear Dr Karen Henderson,

Re: Regulation 28 Report following the inquest into the death of Rose Annie Harfleet

Thank you for raising the Regulation 28 report with us, following the inquest into the death of Rose Annie Harfleet on 30 January 2024 at Royal Surrey County Hospital part of the Royal Surrey NHS Foundation Trust. We would like to extend our sympathy and condolences to Rose's family and friends.

We will respond to each of your concerns in turn.

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

Your concerns relate specifically to the availability of national or local guidance. We are unable to comment directly on this point due to it being outside of the remit of our regulatory scope, and there are other respondents who would be best placed to respond directly to this question.

We do however, acknowledge the lack of understanding of patient needs, and poorer treatment outcomes for patients with a learning disability, in the acute setting, is a known problem. There have been a few research studies undertaken. [How to improve hospital care for children with learning disabilities](#) specifically focuses on children and [Who I am matters](#) is CQC's thematic review into the experiences of autistic patients and patients with a learning disability from 2022.

With unwarranted variation in care and the poorer outcomes sometimes experienced by people with learning disabilities, autism or both it has been recognised trusts need to

sustainably improve many of their services. NHS England introduced the Learning Disability Improvement Standards for Trusts an annual benchmarking exercise to measure trusts performance against a set of standards. These standards provide a benchmark against which all trusts, be they universal or specialist healthcare providers, can measure their performance in delivering services to people with learning disabilities, autism or both, with an aim to drive quality improvement.

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

Speaking with and respecting patients' families is a key aspect of the mandatory learning disability and autism training (aka the Oliver McGowan training) so all clinicians involved should be aware of this. A difficulty with regard to the implementation and regulation of providing this training has been the delay to the publication of the Code of Practice. This will give providers and CQC staff clearer guidance on the requirements of the training and for CQC to regulate. Interim guidance is available on our website.

Nursing and Medical care on the ward

We last assessed the Children and Young Persons Assessment Service Group in June 2024. This was a focused planned assessment which looked at 6 priority quality statements. Parents we spoke with spoke positively about the team approach taken by those caring for their children. One parent spoke about an awareness of the needs of their individual child and how it had been particularly important there had been a multidisciplinary approach, drawing on different people's expertise and knowledge as their child had multiple needs. The assessment only reflected a snapshot of time and from the information provided. It is not a reflection of the experiences of Rose and her mother. We acknowledge this and that this may have been very distressing for Rose's family.

Rose's case is being reviewed in line with the Care Quality Commission's Specific Incident Guidelines. These guidelines describe the process for the organisation to take criminal enforcement action against providers, where a single specific incident, resulted in avoidable harm or exposure to a significant risk of avoidable harm, the incident and resulting harm provides evidence of a serious breach of a prosecutable regulation by the provider and the breach was the responsibility of the provider.

Role and Provision of the Learning Disability Nurse

The nursing team had access to a dedicated paediatric learning disabilities nurse, although this was a time limited service, which resulted in them not being available during Rose's admission.

If you have any questions about this letter, you can contact our National Customer Service Centre using the details below:

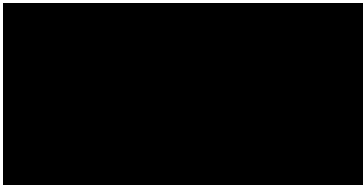
Telephone: 03000 616161

Email: [Enquiries <Enquiries@cqc.org.uk>](mailto:Enquiries@cqc.org.uk)

Write to: CQC Operations South
Citygate
Gallowgate
Newcastle upon Tyne
NE1 4PA

If you do get in touch, please make sure you quote or have the reference above reference number to hand. It may cause delay if you are not able to provide it to us.

Yours sincerely,



Deputy Director