Department
of Health &
Social Care

*From* [redacted]
*Minister of State for Care*

*39 Victoria Street*
*London*
*SW1H 0EU*

Our ref: [redacted]

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

By email: [redacted]

10 July 2025

Dear Dr Henderson,

Thank you for the Regulation 28 report of 13 May 2025 sent to the Secretary of State / the Department of Health and Social Care about the death of Rose Annie Harfleet**.** I am replying as the Minister with responsibility for disabilities and SEND at the Department of Health and Social Care.

Firstly, I would like to say how saddened I was to read of the circumstances of Rose's death and I offer my sincere condolences to her family and loved ones. The circumstances your report describes are very concerning and I am grateful to you for bringing these matters to my attention.

The report raises the following concerns:

- the management of children with profound disabilities within a hospital setting and specifically the lack of relevant guidance;
- consultation with parents and guardians of children with profound disabilities within a hospital setting;
- nursing and medical staff recognition of the importance of listening to the voices of parents and guardians where a patient is unable to advocate for themselves; and
- the adverse impact on care when Learning Disability Liaison Nurses are not offered as a matter of course.

I will outline actions being taken within the Department to address the first three concerns raised in the report. As NHS England oversees workforce within the NHS, it will address the final concern in its separate response and any other relevant actions on the other concerns raised.

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

*Increasing knowledge and awareness of staff*

To improve awareness of learning disability and autism within the health and social care system, under the Health and Care Act 2022, from 1 July 2022 Care Quality Commission (CQC) registered providers are required to ensure their staff receive specific training on learning disability and autism appropriate to their role. This will help to ensure that staff have the right knowledge and skills to provide safe and informed care. To support providers to meet the statutory training requirement, we have been rolling out the Oliver McGowan Mandatory Training on Learning Disability and Autism to the health and adult social care workforce: this specifically highlights the difference that listening to parents can make.

We are aware of the specific challenges faced by those living with rare conditions such as Mosaic Trisomy 17. The UK Rare Diseases Framework was published in January 2021. One of its four priorities is increasing awareness among healthcare professionals. With over 7,000 rare diseases, it is not possible for healthcare professionals to receive comprehensive training on every condition. It is therefore important that they are aware of rare diseases more broadly and are alert to considering them. This includes providing training and resources to enable healthcare professionals to recognise rare diseases in patients and be aware of potential specialist treatment needs, as well as signposting to support and care pathways.

In England, we have now published four action plans setting out how we will address the priorities of the UK Rare Diseases Framework. To ensure delivery and accountability, each action lists an owner, desired outcomes and how we will measure and report on progress. Further information on the 2025 England Rare Diseases Action Plan can be found at www.gov.uk/government/publications/england-rare-diseases-action-plan-2025

*Tailored care*

We expect public services to be adhering to existing responsibilities to provide reasonable adjustments and tailored care for people with specific needs. For example, under the Equality Act 2010, public sector organisations are required to make changes in their approach or provision to ensure that services are accessible to disabled people as well as to everybody else. In addition, each Integrated Care Board must have an executive lead for learning disability and autism who will support the board in: addressing health inequalities; supporting equal access to care across all health services; and improving overall health outcomes.

There is work underway in NHS England to make sure that staff in health settings know when they need to make reasonable adjustments for people. This includes the development of a Reasonable Adjustment Digital Flag, which enables the recording of key information about a patient, including if a person is autistic or has a learning disability, and their reasonable adjustment needs, to ensure support can be tailored appropriately.

In June 2024, NHS England published a Health and Care Passport guidance and template which aims to support personalised care for people with a learning disability and autistic people, including when they go into an acute hospital.

*Long-term ambitions*

The 10 Year Health Plan will set out how the NHS needs to change to ensure everyone has access to high-quality care and how we can enable health and social care services to work better together to provide joined-up care.

As part of the Plan's development, we have been engaging with members of the public and healthcare staff for the last six months to understand what is not working as well as it should and what the potential solutions are. We ran seven in-person deliberative events across the country with the public and we held a specific workshop with people with a learning disability and autistic people to ensure their views were captured. The rich insights we have gathered from these different events and surveys are now being analysed and are informing the Plan to help make the NHS fit for the future.

**The importance of patient voice and parent/guardian advocacy**

All NHS bodies and private and third sector providers supplying NHS services are required by law to have regard to the NHS Constitution when performing their health service functions. The NHS Constitution sets out rights for patients, public and staff. It outlines NHS commitments to patients and staff, and the responsibilities that the public, patients and staff owe to one another to ensure that the NHS operates fairly and effectively.

It also details that patients have the right to be involved in planning and making decisions about their health and care, where appropriate this right includes family and carers of those receiving treatment. Alongside this right, the NHS Constitution also sets out that the NHS pledges to work in partnership with those receiving treatment, their family, carers and representatives.

As part of the government's 10-year plan and transforming the NHS from analogue to digital, the government will create a more modern NHS by bringing together a single patient record, summarising patient health information, test results, and letters in one place, through the NHS App. It will put patients and their advocates in control of their own medical history, meaning they do not have to repeat it at every appointment, and that staff have the full picture of patients' health.

Another important initiative to empower patient voice and parent/guardian advocacy is Martha's Rule. This gives patients and their families who are concerned about deterioration in their physiological condition the right to initiate a rapid review of their case, 24 hours a day, from someone outside of their immediate care team. When requested, this rapid review will inform whether any new or additional action needs to be taken to ensure patients receive the most appropriate care and treatment – which may include escalation.

I hope this response is helpful. Thank you for bringing these concerns to my attention.

Yours sincerely,

[redacted]

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**MINISTER OF STATE FOR CARE**