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02 December 2022

Dear Ms Brown

Re: Regulation 28 Report to Prevent Future Deaths – Asher William Robert Sinclair who died on 08 October 2019

Thank you for your Report to Prevent Future Deaths (hereafter "Report") dated 29 July 2022 concerning the death of Asher Sinclair on 8 October 2019. In advance of responding to the specific concerns raised in your Report, I would like to express my deepest condolences to Asher's family and loved ones and I am very sorry to hear about the tragic circumstances of Asher's death. NHS England are keen to assure the family and the Coroner that the concerns raised about Asher's care have been listened to and reflected upon, in the hope that an incident such as this one never occurs again.

I am grateful for the further time granted to respond to your Report, and I apologise to the family for the delay, as I appreciate this will have been an incredibly difficult time for them.

Following the inquest, you raised concerns in your Report regarding:

1) The care package was not appropriately reviewed and there was no mandatory system of quality checks or formal review when there was a significant change in family circumstances. Quarterly reviews were not carried out, without explanation.
2) Concerns raised by the parents were not taken for discussion to case conference or professional's meetings and were not followed up at all, leaving the situation in the house dangerous.
3) There was a lack of scrutiny or reconciliation of Asher's care package, which could have identified gaps that needed to be addressed.
4) Training for the staff involved was unclear and seemingly not in place or inadequate. The high turnover of staff reported should have highlighted a need for increased training and scrutiny.

The National Tracheostomy Safety Project (NTSP) exists to provide a wide range of resources and materials to support those providing care to these patients, both in hospital and in the community. This also extends to children with permanent/long term tracheostomies where it is recognised that care requires significant skill, knowledge and training. The NTSP has a bespoke and comprehensive paediatric section relevant to this.

I understand that the incident described in your Report occurred in October 2019. Additional work has been done since then to further improve tracheostomy care, including the 2020 Safer Tracheostomy Care program, which was delivered via a Safety Improvement Programme through NHS England (NHSE).

As well as this, the child health outcome programme, commissioned by the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHSE, looked at long-term ventilation in children and young people aged 0-25 years and published their findings in February 2020: https://www.hqip.org.uk/resource/child-health-long-term-ventilation/#.Yys6bnbMKUk. The recommendations in the report included the need for emergency healthcare plans and planning/commissioning integrated care.

I have had sight of NHS North West London's (NWL's) response dated 27 October 2022, which addresses training and supervision, as well as the planning and oversight of care packages. I understand that the NWL children's continuing care team still work within the Department of Health's National Framework for Children and Young People's Continuing Care, published in January 2016. In addition, NWL confirm that a parental agreement has been developed which sets out expectations and responsibilities in respect of parental responsibility, and how parents can escalate concerns regarding the care of their child.

NWL's response also explains the position regarding the dissolution of clinical commissioning groups (CCGs) into new structures called integrated care boards (ICBs), which took place in July 2022, and how commissioning responsibilities are now delivered. I have therefore not addressed this further in NHSE's response.

I would like to provide further assurances on the national NHSE work taking place around the Reports to Prevent Future Deaths. All reports received are discussed by the Regulation 28 Working Group, comprising Regional Medical Directors and other clinical and quality colleagues from across the regions. This ensures that key learnings and insights around events, such as the sad death of Asher, are shared across the NHS at both a national and regional level, and helps us to pay close attention to any emerging trends that may require further review and action.

Thank you for bringing these important patient safety issues to my attention and please do not hesitate to contact me should you need any further information.

Yours sincerely,

[redacted]
National Medical Director
NHS England