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By Email

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Care Quality Commission

Dear HM Coroner Karen Henderson

CQC response to prevention of future death report Mia Louise Guaci-Lamport

Thank you for naming the Care Quality Commission (CQC) as a respondent in the prevention of future death report issued on 20/10/2024 following the death of Mia Louise Guaci-Lamport.
We would like to extend our sincere condolences to Mia's family.

The Children's Trust – Tadworth provides a residential children's home for children and young people with profound and multiple learning disabilities, a residential rehabilitation service for children and young people with acquired brain injury and a short breaks service. Ofsted are the lead regulator for The Children's Trust because of its status as a children's home. The service is also registered with the Care Quality Commission but only for the regulated activity of treatment of disease, disorder, or injury. Therefore, the CQCs remit extends to regulation of this regulated activity only. CQC does however work closely with Ofsted as partner regulator.

We note that the concerns are as follows:

1. **Lack of appropriate monitoring of Mia during the night:**

Mia's underlying illness caused seizures which were multifocal, complex and variable from tonic-clonic, myoclonic to cluster and absence seizures. Her care plan stipulated that carers should enter her room every 15 minutes to undertake visual observations throughout the night to ensure Mia was in a safe position, was breathing and not at risk of asphyxiation. However, this did not take place as frequently as specified. Moreover, it was common practice amongst some carers to review images from a video monitor placed over Mia's cot rather than direct visualisation despite it being recognised that the monitor was insufficiently sensitive to reassure the carer that Mia was breathing, seizure free and safe from asphyxiation

On 11th September 2023 we received a notification from the registered manager at The Children's Trust (TCT) regarding Mia's death where we immediately requested a copy of TCT's initial investigation and the outcome of the police report. The police report stated that Mia's death was not being treated as a criminal investigation. We liaised closely with Ofsted, who also inspect and regulate accommodation, care and education at TCT. We were aware that they had scheduled an inspection imminently. Taking into consideration these factors, we made the decision to wait until the outcome of Ofsted's inspection was known and could be considered alongside findings from TCT's own external investigation before a CQC inspection.

Ofsted inspected TCT in September 2023 and rated them good in all areas. They issued one requirement of "Individual care plans must be explicit in relation to the levels of staff supervision required to meet children's needs. Where this includes the use of visual monitoring, this needs to be included in children's individual plans. Ensure that these plans are accessible and understood by all staff."

On 18th October 2023 CQC requested the outcome of the external investigation from the registered manager at TCT. This wasn't available, but TCT shared the findings with CQC of the internal investigation. Alongside the evidence of findings from the Ofsted inspection the CQC made the decision to await the external investigation findings before scheduling an inspection.

On 12th December 2023 CQC requested an update regarding the progress of the external investigation. TCT leadership team notified CQC they were not happy with the standard of the first external investigation report due to it not being sufficiently comprehensive and that they had commissioned a second external investigation. A comprehensive CQC inspection was scheduled for February 2024.

TCT continued to update CQC on the progress of the second external review. On 11th January 2024 we received an email from the registered manager at TCT to inform us they had now commissioned the second external review and terms of reference had been agreed.

In December 2023 CQC had received key information and started to plan for an inspection in February. On February 20th to 21st 2024 the CQC undertook a comprehensive inspection of TCT as part of our regulatory response to the notification of Mia's sad death. The inspection looked at all five key questions of whether TCT is Safe, Effective, Caring, Responsive and Well-led. (Please see attached PDF). CQC do not provide ratings for children's homes that are registered with Ofsted, as per our policy.

During the inspection we reviewed a selection of audits and 18 children's records, and we did not find any evidence of care deviating from that stipulated in the care plans. However, when speaking with staff we found a variance in their understanding of how visual checks should be undertaken. Therefore, we recommended that TCT should strengthen the detail of description of one to one care and observations related to overnight care within children and young people's care plans. TCT leaders informed the CQC that processes were immediately implemented to ensure all house managers were assured staff understood what actions were required during a visual check and children's care plans were updated accordingly.

CQC assumed enforcement responsibility for health and safety related serious incidents concerning people using services in health and social care settings in England in April 2015. This is where people using services (SUs) have sustained avoidable harm including death, have been exposed to a significant risk of avoidable harm, or have suffered a loss of money or property as a result of a failure by the Registered Person. The 'Registered Person' (RP) is the Registered Provider and/or Registered Manager. We used the CQC specific incident guidance to make a decision about:
1. Does the information about the specific incident raise concerns about ongoing risk of harm to users of the service which CQC should inspect?
2. Does the information about the specific incident suggest the harm sustained was avoidable and may have resulted from a breach of a prosecutable fundamental standard?

When we received each new piece of information regarding Mia's case, we reviewed this against our specific incident guidance and concluded that there was not a breach of prosecutable fundamental standard.

In July 2024 following the coroner's inquest and information from the independent investigator report, CQC requested monthly updates from TCT regarding the providers audits of frequency of monitoring of children and their Paediatric Early Warning System (PEWS). The audits and actions taken, provided CQC with assurance the leadership team continued to take positive action to address any gaps in practice that the audits identified.

2. **Medical Care provided to Mia:**

Mia's medical records at TCT were neither comprehensive nor easy to understand and did not conform to the expected standard in NHS general or hospital practice to ensure accurate and contemporaneous medical care was being reviewed and documented. Mia was a 'looked after' child with complex and challenging health needs and could not contribute or make decisions for herself. The independent investigator found regular PEWS (Paediatric Early Warning Scores) assessments were not undertaken to ensure Mia's wellbeing despite it being within her care plan. There was no documented evidence that a multidisciplinary clinical review was regularly, if at all, undertaken to ensure Mia's risk was regularly assessed, appropriate monitoring was in place, and care provision was meeting her needs. Mia was reviewed by a 'privately-funded' consultant employed by but working independently of Great Ormond Street Children's Hospital as and when requested by the medical staff at TCT. The consultant had no terms of reference and did not take responsibility for Mia's ongoing care and was consulted only in relation to adjustments in her medication for seizure control. Due to financial constraints the consultant's service level agreement was temporarily terminated and not available from April to October 2023. In this context, Mia was not under a specialist NHS paediatric neuro-consultant to ensure her ongoing medical needs conformed to expected practice nationally and for an independent consultant outside of TCT to have regular oversight and co-ordinate investigations and any further multi-disciplinary management she may need given this progressive life-limiting condition.

During the 20th – 21st February 2024 inspection the CQC reviewed 18 PEWS charts and found these had been fully documented with the correct escalation if the PEWS scores were escalating. We found: *"evidence in children and young people's records that staff assessed, monitored, and managed risks well. Care plans we reviewed, were comprehensive and covered all aspects of the child and young person's life such as moving and handling, sleeping positions, medicines, and specific conditions such as epilepsy management".* Please see attached inspection report.

We have since received three months' worth of PEWS audits which shows a 95-97% compliance rate with evidence of learning and improvements where required.

As per [redacted]'s witness statement it is our understanding that Mia was not without specialist NHS paediatric neuro-consultant care at any time as the paediatric neurology department at St George's Hospital (SGH), Tooting is the tertiary centre for paediatric neurology in the region. There is a shared care arrangement between the neurology department and the SGH and the paediatric department at Epsom hospital, therefore if Mia had required any specialist neurological care this would have been provided by Epsom hospital.

Prior to the inspection our review of evidence did not identify any deficits in care regarding children having 'privately funded consultants', therefore this was not an active line of enquiry. However, with regards to regular oversight and co-ordination of investigations we found during the February 2024 inspection that *"the medical team have monthly complex case discussions. This is an opportunity for the full multidisciplinary team to learn from each other and reflect on cases that have gone well and identify areas for improvement".* We found all children were able to access NHS services either through their local NHS hospital or the tertiary centre they were receiving treatment from. The February 2024 report noted "*The doctors at the Children's Trust attended transition planning meetings and advocated for tertiary and GP care. They oversaw the transition planning and referred to specialist clinics as required".*

Following the Coroner's inquest, we requested an update regarding TCT's governance arrangements around independently practicing consultants. TCT told us that all the consultants they were currently using all had substantive posts within an NHS trust, but that they were reviewing their governance processes regarding if a clinician did not have a substantive post within an NHS trust.

3. **Senior management, Children's Trust, Tadworth:**

The lack of a robust and adhered to care plan for night observations for Mia mirrors the same concern in the PFD report I issued following the Inquest touching on the death of Connor Wellsted at TCT in 2022. The Independent investigator commissioned by TCT highlighted ongoing clinical governance limitations including the initial management and investigation of Mia's death, delay in fulfilling the Duty of Candour' obligations, ongoing staff training, ensuring robust

procedures were in place alongside regular audits of clinical practice. These are the same issues highlighted in the PFD report I issued touching on the death of Connor Wellsted two years previously.

Since the sad death of Connor Wellsted in 2022 and Mia's death, CQC have undertaken three subsequent inspections which have demonstrated that TCT have taken the appropriate actions to ensure the governance processes around night time observations have been strengthened. CQC is assured with regard to it's own regulatory functions, by the actions taken by TCT. Specifically this includes to strengthening the frequency of monitoring policy and increased their audits of the implementation of this policy.

During the February 2024 inspection we found all staff had received the appropriate level of training relevant to their role and the healthcare activity they deliver.The education team provided child and young person specific training as the need arose.
We also noted that "*staff demonstrated knowledge of the Duty of Candour, to be open and transparent with people including when things go wrong with their care and treatment".* In Mia's case there was a delay in executing the Duty of Candour, however the CQC did not deem this instance to be a breach of Health and Social Care Regulations.

CQC have seen evidence of a strengthened learning culture at TCT through inspection and routine engagement conversations. We have seen progress in their action plan against the recommendations made by CQC from both the January 2020, May 2021 and February 2024 inspections and the external investigation of Mia's death. In addition TCT had a Frequency of Monitoring Policy in place since July 2022 which continues to be reviewed and updated. TCT have taken appropriate action to ensure they are not in breach of Regulation 12 safe care and treatment.

The senior leadership team at TCT continue to be receptive and responsive to challenge and proactive in providing information to CQC to demonstrate how improvements have been made in response to incidents, complaints and inspection findings.

The CQC will continue to work closely alongside Ofsted to monitor and inspect according to our current inspection methodology and continue to respond to any emerging risk identified through monthly data assurance reports, regular engagement meetings, notifications or whistleblowing reports.

Yours sincerely

[redacted]

[redacted]
Deputy Director Multiagency Operations
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Care Quality Commission