Regulation 28: Report to Prevent Future Deaths, Mia Gauci-Lamport

Coroner's Concerns

The matters of concern 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.

2. Mia's medical records at The Children's Trust 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. Regular PEWS (Paediatric Early Warning Scores) assessments were not undertaken to ensure Mia's well-being 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 The Children's Trust. 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 The Children's Trust to have regular oversight and co-

ordinate investigations and any further multi-disciplinary management she may need given this progressive life limiting condition.

3. Senior management at The 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 Prevention of Future Deaths report I issued following the Inquest touching on the death of Connor Wellsted at The Children's Trust in 2022.

   The Independent investigator commissioned by The Children's Trust 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.

Regulation 29: Response from The Children's Trust, Action to Prevent Future Deaths, Mia Gauci-Lamport

The tragic death of Mia has deeply affected all of us at The Children's Trust and our thoughts continue to extend to Mia's family and loved ones. We fully acknowledge the importance of the coroner's concerns raised in the Prevention of Future Deaths report and take this and every opportunity to review our practices and ensure that lessons are learned.

We are committed to continuously improving our services, strengthening our systems, and ensuring the highest standards of care for the many families and carers who put their trust in us, and to working in partnership particularly with the children in our care and their families.

We have taken immediate and comprehensive steps to address the areas raised in the report. We acknowledge that whilst significant improvement work has been undertaken in these areas in recent years, further work was, and is, still needed. This response outlines the actions already taken and the improvements we continue to make.

We remain focused on creating an environment where children with complex needs receive care that meets the highest standards, and we are fully engaged with external stakeholders to ensure that our practices are aligned with the most current guidelines and evidence-based practice. Since the inquest, The Children's Trust has been inspected by Ofsted Care who rated the residential care provided to the children and young people as Good.

Action Taken by The Children's Trust

Review and Update of Care Plans and Monitoring Protocols

A comprehensive review of our monitoring protocols and individualised care planning process has been undertaken which has led to several critical actions being identified, all of which are now overseen by robust internal governance:

- Policy and Clinical Guideline: The Frequency of Monitoring Policy has been initially reviewed and updated to ensure it is clear and consistent and can be individualised for each child through specific clinical guidelines. This ensures monitoring practices are personalised to meet each child's unique needs and based on

individualised risk assessments. Further work is now needed to align the policy with national best practice relevant to the unique care setting at The Children's Trust. This work has commenced and requires wider input and critique to ensure that a significant and safe revision to our approach and policy is designed and implemented.

- Monitoring Tools: A review of monitoring tools, including video surveillance and wearable sensors, has been completed. We continually ensure that these tools are appropriate for each child's needs and used correctly to provide effective oversight without replacing appropriate checks. This initial action is complete and is now continuously reviewed and audited in line with evidence-based practice.

- Individualised Care Plans: We have made certain that care plans are clear, individualised, and regularly updated based on the child's current needs and challenges and aligned to the PEWS (Paediatric Early Warning Scores). These updates ensure that the monitoring of children is consistent, personalised, and aligned with the latest clinical guidelines. This initial work is complete and is now continuously reviewed and audited in line with our policy and best practice.

- Shift Handover Protocol: A revised Shift Handover Protocol has been introduced to ensure that the level of supervision and observation required for each child is understood and clearly communicated during shift changes. Additionally, the last set of clinical observations from the prior shift are recorded and discussed at handover, ensuring a seamless transition and continuity of care. This protocol has been embedded across The Children's Trust and is subject to continuous review and audit to ensure compliance.

- Frequency of Monitoring and PEWS Practice Audits: We have implemented new Frequency of Monitoring Practice audits overnight, conducted by Clinical Site Managers. This ensures continued compliance with the monitoring and observations policies. These audits are complemented by monthly quality walks to ensure the consistent implementation of care plans and protocols. This additional assurance mechanism is built into roles and responsibilities and findings from these audits feed into the broader clinical governance framework.

- Reporting and External Oversight: The results of relevant audits are reported to both The Children's Trust regulators, The Care Quality Commission and Ofsted, monthly, ensuring external oversight and accountability. Furthermore, we are working with the wider health and social care system to continually revise and improve our protocols, ensuring they are evidence-based, benchmarked, and consistent with the best practices in residential settings. This work continues and is taking place through existing NHS governance frameworks.

Integration and Multidisciplinary Working

Recognising the need for greater integration with NHS services, particularly for children with complex health conditions such as epilepsy, we have already taken significant steps to strengthen our collaboration with NHS partners to ensure the children and young people in our care have equal access to NHS resources and expertise:

- Enhanced NHS Integration: The Children's Trust is actively working with primary, secondary and tertiary NHS services to ensure that children in our care receive timely and regular access to care. We are working with the wider health and social care system to formalise clearer referral pathways and improving coordination with NHS specialists to ensure that all clinical needs are addressed promptly. This work has commenced and continues through existing NHS governance frameworks.

- Reducing Reliance on Private Consultants: We are actively reducing our reliance on private consultants for ongoing care, particularly in areas such as epilepsy management, and are working to ensure that children receive care that is fully integrated within the NHS. We have required wider health and social care system support to ensure equitable access for the children and young people in our care and this work continues.

- Multi-disciplinary Care Model: We are working with the broader NHS system to improve integration across the whole care pathway and ensure that this is multi-disciplinary across medical, nursing and care and therapy, and not focussed solely on the medical care for the children and young people. Whilst we have a strong internal multi-disciplinary care model focussed around the care of the children, we have also taken the opportunity to commence a detailed review of our internal model alongside broader integration.

- Medical records: We continually audit our medical records in line with NHS standards and achieve high compliance against these. As an organisation sitting outside the NHS, health record integration is complex and an ongoing area of focus for us with our wider health and social care system partners. Medical record audits continue regularly to ensure our ongoing compliance in this area.

Leadership and Governance Improvements

The Children's Trust is committed to maintaining and improving robust governance and oversight systems. We have initiated a series of improvements:

- Strengthened Governance Framework: We have reviewed and begun to refine our clinical governance structure to ensure that all care practices are subject to rigorous oversight and that systems are in place to monitor adherence to protocols and standards. This includes strengthening review processes and ensuring that leadership is engaged in overseeing the implementation of improvements. This programme of work is in process with some immediate actions taken.

- Regular Audits and Reviews: To support sustained improvement, we have introduced regular audits to assess the quality of care, the implementation of and adherence to care plans, and the effectiveness of our monitoring practices. This work continues and is scrutinised both internally and by our external regulators and commissioners.

- Thematic review: We have undertaken a thematic review of all serious incidents and near misses within a specific timeframe. The themes and trends identified through this review have resulted in dedicated workstreams being embedded into the existing governance structure. The thematic review is currently in the final stages of completion and has focussed on the embedding of continuous quality improvements.

System-Wide Risk Summit

In response to the Coroner's Regulation 28 report, The Children's Trust called a System-Wide Risk Summit which was held on November 14, 2024. The summit brought together a wide range of external stakeholders, including NHS England, NHS providers as well as social care partners, commissioners, regulators, and expert consultants.

The summits' goal was to discuss the concerns raised by the coroner and identify actionable steps to strengthen care practices, ensuring that The Children's Trust's processes are aligned with national standards and evidence-based practice.

The summit focused on two key areas:

Medical Care Provision for the Children and Young People:

- The summit discussions highlighted the challenges in relation to the integration with broader NHS paediatric services for the children within residential care at The Children's Trust. This was particularly explored for complex conditions such as epilepsy. It is essential, for us and the wider system, to recognise that children in our care are entitled to the same standard of, and access to, NHS services they would receive elsewhere. The identified gap in access to NHS paediatric specialists in the management of epilepsy, is being urgently addressed as part of ongoing work with system colleagues. The Children's Trust has taken proactive steps in collaboration with NHS partners to ensure equitable access to NHS services, upholding the parity of care and ensuring children receive appropriate care alongside and enhancing the medical provision provided by The Children's Trust.

Monitoring and Observation of Children and Young People

- The summit examined the current practice and policy in relation to monitoring and observation, particularly around night-time care, and explored ways to ensure that care plans are adhered to consistently as well as what is appropriate within a residential care setting for medically stable children. There was clear recognition that wider health and social care system support as a critical friend is readily available in relation to this complex issue, and that the current policy and processes in place far exceed those within a variety of healthcare settings. Further revisions to the policy are planned following ongoing engagement with system partners.

Ongoing Actions

To ensure that improvements are embedded within The Children's Trust, the following ongoing actions (also detailed within the narrative above), have been identified:

1. Integrated Multi-Disciplinary Care Model
    - Action: Further strengthen integration with NHS services to ensure equal and timely access to care for children with complex health needs.
2. Monitoring and Observation
    - Action: Further revise monitoring protocols and care plans in line with best practice and with wider system engagement and support.
3. Governance and Policy Development
    - Action: Further strengthen clinical governance frameworks and ensure ongoing and robust oversight of all care practices.

Summary

We remain committed to ensuring the highest standards of care for all children and young people at The Children's Trust. We fully recognise the importance of the concerns raised in the Coroner's Regulation 28 report and have taken immediate steps to enhance our practices and systems. Through collaboration with our NHS and wider system partners, continuous engagement with stakeholders, children and families, and a strong focus on improving clinical governance, we are confident that these changes will result in tangible improvements to the care we provide.

We remain fully engaged in this process and will continue to review and refine our practices to ensure that all children receive the safest, highest quality care possible.