

Private and confidential

Nursing and Quality Team

Kent House
81 Station Road
Ashford
Kent
TN23 1PP

Sent via email/post

13th June 2022

Dear Ms Wood,

Response to Regulation 28 Report to Prevent Future Deaths, dated 12th March 2022
Re. Samuel Alban Stanley

Following the Inquest opened on the 14th of May 2020, the NHS Kent and Medway Clinical Commissioning Group (CCG) received the Regulation 28 Report touching on the death of Samuel Alban Stanley.

The CCG while not in attendance at the Inquest would like to take this opportunity to extend their condolences to the family and friends of Sammy following his tragic death.

Clinical commissioning groups were established as part of the Health and Social Care Act in 2012 and are responsible for commissioning healthcare services for their local populations. They are also system leaders with a key role to play in improving the quality of care and their role does not sit in isolation. However, they are not directly responsible for the provision of services and nor are they responsible for the commissioning of social care services, which in Kent is the responsibility of Kent County Council.

Notwithstanding this and recognising the coroner's comments regarding the need for closer communication between agencies, the CCG acting in good faith, has liaised with both Northeast London NHS Foundation Trust (NELFT), Kent County Council (KCC) in order to respond to the concerns cited.

- 1. Concerns that more support should have been available to Sammy and his family for the rare nature of conditions such as Prader-Willi syndrome.**

The Kent and Medway health and care system (the system) has taken steps to learn and embed changes from this case to improve the experience of patients in the future.

[Redacted]

Training has been provided to staff within the Children's and Young Person's Mental Health Services (CYPMHS) at NELFT, specifically on Prader-Willi syndrome. NELFT has reported that training was received by 400 staff from February 2021.

Due to the rarity of the condition, reviews have been put in place to consider high complexity cases that may not meet the criteria for Neurodevelopmental Services. In future, where these very complex cases present, joint assessments will take place between the CYPMHS and the Neurodevelopmental (ND) and Learning Disabilities (LD) services, to combine the expertise of the services and generate a joint working arrangement to address the needs of the patient. NELFT have stated that this process will ensure that joint working is fully embedded and that the assessments fully include a holistic view of the young person's needs, risks, and presentation.

Clinical harm reviews on the highest risk and most vulnerable patients have also been introduced across social care and NELFT, as a way of ensuring that patients are identified as early as possible and given additional support if required.

Further training has also been designed to support staff in the CYPMHS to provide more support of a combined psychological and medical nature to people suffering with Autistic Spectrum Disorders (ASD): the senior clinical leads for the service completed this training in December 2021.

2. Concerns that the local authority Kent County Council (KCC), were aware of the high-risk situation at Sammy's home but did not have adequate knowledge on what support could be accessed by the family and did not robustly respond to the change in needs during the pandemic when the support available became more limited.

KCC have taken several steps to ensure better engagement with the local mental health resources. The working protocol between teams at the local authority and NELFT has fundamentally changed to ensure that they are now party to one another's multidisciplinary meetings as a matter of course. This allows for improved information sharing between agencies, rapid and accurate decision making and enabling access to resources

Also, working with the wider healthcare system, KCC have taken steps to ensure that they are improving services for children and young people. The criteria for services have been reviewed specifically with regards to neurodiversity, which has already led to several children and young people being transferred to services that better meet their needs.

A large amount of work has also been undertaken regarding the suicide prevention strategy for young people since the death of Sammy. This includes the lead for KCC actively working with healthcare providers and the CCG to identify high-risk cases and provide support in the home to avoid admission where this is safe to do; and to ensure that families have access to the services they need. Meetings in relation to these cases have representation from the relevant stakeholders across the system. They proactively discuss any placement breakdown and consider how best to support and deliver potential solutions.

The CCG has also established a 'Dynamic Support Database', which has been developed to enable all statutory partners to better understand the needs of children and young people with Learning Disability and Autism. Consent to details being added to the database is given and the CCG holds this list to ensure it can support patients who may need additional services or help in future. It is a way of helping managing system risk for patients with complex needs and helps facilitate system ownership of all these cases, to ensure provision of the right help and support at the right time, in collaboration with the patient and their family.

During the Inquest, it was highlighted that there was a lack of knowledge and understanding of the rights of parent carers of a disabled child to request a separate assessment of their needs; how to carry out the assessment and where the information is held and how needs may be met through Direct Payments. In response to this, KCC has delivered training to families, covering the rights of parents of disabled children to request a Parent Carer assessment, separate to their child's assessment. They have also introduced new Parent Carer Assessment forms so that social work staff consider and consult with parents of disabled children as to whether a separate assessment of their needs is required, or the parents/carers are content for their needs to be included in the Child and Family Assessment (majority).

3. Concern that there was a lack of psychosocial and psychological therapies offered in this case. This was compounded by the information shared that NELFT may not have been commissioned to provide anything other than a diagnostic service for those presenting with autism and learning disabilities rather than an overt mental health issue.

In terms of the commissioning of services, the CCG actively works with partners across the health system to ensure gaps do not exist and that pathways are in place to cater for the presentations and needs of the local communities it serves. NELFT *are* commissioned to provide more than just diagnostic services including psychological and psychosocial interventions, but the CCG acknowledge that mental health services are under extreme pressure, with increasing referrals that have significantly peaked during and post pandemic. Therefore, the CCG is actively working with NELFT to ensure that services are developed to meet the needs of all children and young people and to identify areas where the service offer can be strengthened and have increased significant levels of investment to help address this.

Since 2019/20 additional investment of £2.1 million has been made into local Neurodevelopmental services. Whilst unfortunately this did not prevent the tragic death of Sammy, it has subsequently generated improvements to services provided.

This investment includes the commissioning of Nurture UK to deliver an 'inclusion' programme in schools to improve educational outcomes for children with Special Educational Needs and Disabilities (SEND). Inclusive schools contain the following elements:

- a belief that all children have the potential to learn and grow
- the ability to respond to the cultural and/or socio-economic needs of the students
- the ability to support positive behaviour in and out of the classroom

- a dedication to seeing each child as an individual
- the modification of curriculum and activities to include all students

“Together with Parents’ is another service which is being jointly funded between the CCG and KCC to provide better support to families in the community. The service was co-produced with parents, carers and professional partners and delivers local support to parents and carers whose child has either received a diagnosis or are awaiting diagnosis for a neurodevelopmental condition. The new service is to ensure parents can access support and information in a timely way before reaching crisis point.

With regard to the psychological treatment offered in this specific case during the episode prior to Sammy’s sad death, the CCG has been assured that NELFT undertook an assessment of need. Sammy’s escalation of need occurred at onset of the pandemic, when statutory services were severely limited in terms of the care they could provide, and the guidance around the management of clinically vulnerable children during the pandemic was in an embryonic stage. Sammy was under the care of a consultant psychiatrist who regularly reviewed and monitored the prescribing of medications. KMCCG understanding of the clinical opinion and expertise of Sammy’s needs was that the psychological intervention of cognitive behavioural therapy would not have been appropriate or effective to meet his needs and hence the more psychosocial intervention of Non Violent Resistance was offered. NVR is an evidence-based psychosocial intervention to support parents in responding to their child’s more challenging needs.

4. Concern that the communications between agencies in this case were inadequate.

As detailed above, several new processes have been put in place to improve the way in which the relevant agencies communicate in a timely manner. Multidisciplinary meetings between agencies are now a matter of course and fundamentally the standard operating procedure for CYPMHS has been amended to ensure that the communication and sharing of expertise is embedded as a business-as-usual activity. This has been emphasised with regards to LD cases specifically, due to the complexity of these, as has the need to involve numerous agencies as standard practice.

KMCCG have worked with NELFT, acute and community trusts, KCC, NHS England and wider partners to improve communications regarding children and young people who have the most complex presentations and are considered at risk. KMCCG has invested in new strategic leadership posts whose role is to drive improved dialogue across agencies and to provide a route for rapid escalation and resolution. Since Sammy’s death, KMCCG have worked in collaboration with system partners to develop and implement shared Kent and Medway escalation policy and protocols. This enables rapid identification of children and young people who need senior leader oversight to ensure appropriate care.

5. Concern that children in other areas with neurodevelopmental needs may be excluded from accessing the care and treatment they need to keep them safe.

Since Sammy's death, KMCCG has made investments in posts and mechanisms to improve the offer for children and young people with neurodevelopmental presentation. A number of joint posts have been created across the Local Authority and Primary Care so that children and young people with additional needs are identified early and care is coordinated rapidly around the child and family.

Kent partners have been successful in bidding for and mobilising the National NHS England Designated Key Worker Early Adopter programme. This team is based in KCC and is a partnership project across health, the Local Authority and NHSE. The Designated Key Workers provide practice consultancy to multi agency partners/networks and case coordination for children and young people with complex neurodevelopment. The team work in conjunction with the KMCCG Learning Disability and Autism team to ensure referrals to the Dynamic Support Database and CETR processes has better supported the needs of children and young people to avoid placement breakdown and admission to T4 services.

There continues to be developments and innovation focussed on earlier intervention and support for families who have children and young people with neurodevelopment needs. Examples of which include new programmes within schools across Kent to promote inclusive practice and reduce exclusions. Piloting early identification and support of children and young people through a Primary Care multi-disciplinary approach utilising Care Navigators to support meeting the holistic needs of a family.

As a health and care system we are determined to ensure we learn from Serious Incidents such as this tragic case and continue to take appropriate action, as outlined above, to prevent similar occurrences from happening in the future.

From July 2022, Integrated Care Boards will succeed CCGs across the country. The Boards of these organisations will include Partner Members from Local Authorities and NHS Providers, with a focus on greater collaboration and more seamless joint decision making

Yours sincerely,



Executive Chief Nurse
Kent and Medway CCG