REPORT TO PREVENT FUTURE DEATHS

	REGULATION 28 REPORT TO PREVENT FUTURE DEATHS **THIS REPORT IS BEING SENT TO:** **1. The Secretary of State for Health and Social Care** **2. NHS Kent and Medway Clinical Commissioning Group**
1	**CORONER** I am Catherine Wood, assistant coroner, for the coroner area of North East Kent.
2	**CORONER'S LEGAL POWERS** I make this report under paragraph 7, Schedule 5, of the Coroners and Justice Act 2009 and Regulations 28 and 29 of the Coroners (Investigations) Regulations 2013.
3	**INVESTIGATION and INQUEST** On the 14th May 2020 I opened an inquest into the death of Samuel Alban Stanley. At the inquest, which lasted nine days and heard from many of those involved in Sammy's short life, I concluded on 29th November 2021 with a narrative conclusion "Samuel Alban-Stanley died as a consequence of injuries sustained during an episode of high-risk behaviour, related to his Prader-Willi syndrome, on a background of inadequate support from the Local Authority and Mental Health Services."
4	**CIRCUMSTANCES OF THE DEATH** (1) Samuel Alban Stanley was the eldest of four children and a loving caring little boy who was cared for by a dedicated family. Unfortunately, he suffered from Prader-Willi syndrome, a rare genetic condition with a known association with behavioural problems which often increase with age. Not unexpectedly as Sammy got older his behavioural problems increased and at times these were incredibly high risk including trying to jump out of moving cars, building windows and into the sea. Police intervention was required, at times, to assist the family in managing his behaviour. (2) In 2018 he and his family moved to Kent and after a prolonged period, including appeals against decisions to place him in a mainstream school, he was placed in Laleham Gap school in March 2019 and he thrived in the supportive environment provided by the school. Concerns about his behaviour remained and he was at risk of significant harm when he was in a distressed and emotional state. His family struggled to manage his high risk behaviours in particular at times such as the school holidays and they had repeatedly requested assistance from social services. (3) In March 2020 he was deemed to be vulnerable to the effects of Covid 19 and advised to shield which meant he no longer had access to the supportive school environment. A child in need meeting was held on 17 April 2020 to discuss support for the increased risks of Sammy being at home but no support was provided. (4) On 22 April 2020 Sammy left his house early in the morning and was seen to [redacted] and despite prompt treatment and attention he died in Kings College hospital on 26 April 2020 as a consequence of his injuries.

5	**CORONER'S CONCERNS** During the course of the inquest the evidence revealed matters giving rise to concern. In my opinion there is a risk that future deaths could occur unless action is taken. In the circumstances it is my statutory duty to report to you. The **MATTERS OF CONCERN** are as follows. – (1) Evidence given at the inquest by Professor [redacted] from Great Ormond Street made it clear that the episodes of behavioural difficulties experienced by Sammy were inherently a part of his Prader Willi syndrome. He also indicated that it was not uncommon for the parents of children with behavioural difficulties associated with their underlying disease to inform him that they did not have adequate support. He opined that whilst the risk cannot be eliminated it could be managed through a combination of psychosocial intervention, sometimes with medication and care. He told the court that more support should be available to the families of children with rare diseases such as Prader Willi syndrome. (2) Evidence was given at the inquest that the social workers from Kent County Council were fully aware of Sammy's high-risk behaviour and had on several occasions referred him to their Children with Disabilities team who refused to assess him. Sammy's behaviour was also having an adverse impact on his three younger siblings. His mother had repeatedly reported that she could not keep Sammy safe without support and had sought assistance from state agencies, Charites and done as much as she possibly could herself. Social workers took steps to try to access support for his family to enable them to care for him but the way services were managed meant those involved had little knowledge of what was available. One social worker gave evidence that Sammy's behaviour had escalated between August 2019 and January 2020 when he did not have access to support in the home. However, despite being aware that Sammy needed more support to provide wrap around care before and after the school day only very limited support was funded from the end of January 2020. When the advice was given for him to shield in March 2020, due to the Covid 19 pandemic, he now had to isolate and was without the supportive school environment yet no replacement support was provided despite the need being obvious. (3) There was evidence given that the mental health team at North East London Foundation Trust were also aware of Sammy's high-risk behaviours. Support had been provided by a psychology student in the past and he had reportedly responded well to mindfulness therapy and the de-escalation techniques employed by his family. Psychosocial interventions were not offered by the Mental Health Trust and a Care Education and Treatment Review was suggested but not implemented before Sammy's death. The court heard that such interventions may not have been successful but, in any event, North East London Foundation Trust had not been commissioned to provide anything other than a diagnostic service to children presenting with autism and learning disabilities rather than an overt mental health diagnosis. (4) The evidence at the inquest also revealed that communication between agencies involved in his short life was inadequate. It is possible that had information been shared in a timely manner and actions taken as a result then more support could have been provided to Sammy and his family. Had he, and his family, had more practical help and support this may have made a difference to his high-risk behaviour and ultimately his death. (5) It was clear at the hearing that locally Kent County Council had taken steps to change the way their services were delivered following Sammy's death but it is predictable that a similar incident may arise in other areas if children with

	complex neurodevelopmental needs are excluded from accessing the care and treatment they require to keep them safe.
6	**ACTION SHOULD BE TAKEN** In my opinion action should be taken to prevent future deaths and I believe you have the power to take such action.
7	**YOUR RESPONSE** You are under a duty to respond to this report within 56 days of the date of this report, namely by 11th April 2022. I, the coroner, may extend the period. Your response must contain details of action taken or proposed to be taken, setting out the timetable for action. Otherwise you must explain why no action is proposed.
8	**COPIES and PUBLICATION** I have sent a copy of my report to the Chief Coroner and to the following Interested Persons namely the family, Kent County Council and North East London NHS Foundation Trust. I am also under a duty to send the Chief Coroner a copy of your response. The Chief Coroner may publish either or both in a complete or redacted or summary form. He may send a copy of this report to any person who he believes may find it useful or of interest. You may make representations to me, the coroner, at the time of your response, about the release or the publication of your response by the Chief Coroner.
9	**12 March 2022**  **Catherine Wood** **Assistant Coroner** **North East Kent**