Kent Safeguarding Children
multi-agency partnership

CHILD SAFEGUARDING PRACTICE REVIEW

James

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Lead Reviewer: Karen Perry

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CONTENTS

1. Introduction page 2
2. Summary of learning page 2
3. Details of the family and the child's story page 3
4. Thematic analysis page 5
5. Parents' comments page 20
6. Positive practice page 20
7. Conclusions page 21
8. Recommendations page 22

INTRODUCTION

1.1. This Child Safeguarding Practice Review is in respect of James who was born at home. He was pronounced dead at hospital on the same day due to infection[1]. Whilst his chances of survival might have been better had he been born in hospital, due to the availability of more prompt resuscitation, he might still have died. The review was commissioned partly due to a belief that Mother may have discharged herself from hospital the evening before James's birth against medical advice, which has since been discovered not to be correct. Pregnant women in the UK are entitled to make autonomous decisions in the same way as any other person, even if healthcare professionals believe these decisions are unwise as long as they have full mental capacity. However, the Rapid Review[2] identified that there was potential learning associated with Mother's learning disability and effective service delivery, particularly in a crisis. Mother had not engaged well with some aspects of antenatal care; refusing medication and blood transfusions necessary for the health of both her and the baby. Father had not facilitated these.

1.2. Kent Safeguarding Children Multi-agency Partnership (KSCMP) will ensure that learning is widely disseminated locally and will publish this report on its website for at least 1 year. To avoid unnecessary disclosure of sensitive information, details in this report regarding what happened focus only on the facts required to identify the learning. The primary focus of this Child Safeguarding Practice Review is multi-agency involvement from September 2022 (when Mother's pregnancy was identified) until March 2023 (when James was born and died).

1.3. KSCMP agreed to undertake this review using a learning model which engages frontline staff and their managers in reviewing cases, focussing on why those involved acted as they did at the time and aiming to identify any systems issues[3] which affected this case and may impact in future on other children in the area. Family members were also offered the opportunity to speak to the lead reviewer. The parents provided some brief comments via an intermediary; their comments are included in section 5.

2. SUMMARY OF LEARNING

2.1. All learning points are listed in section 4, at the end of each theme. What follows is a summary of the most significant learning from this review. The prevalence of diagnosed learning disability in the general population is approximately 2%.[4] This means that non-specialist practitioners will have relatively infrequent contact with people who have a diagnosed learning disability. A proportion of non-specialist practitioners are not clear about the difference between learning difficulties and learning disabilities. These phrases are not interchangeable. In addition, a proportion of non-specialist practitioners do not have a clear understanding of the terminology for and implications of different levels of learning disability. Persons like Mother, who have a "moderate" learning disability are likely to need support from someone to function adequately in areas of their lives. Especially if they are not receiving such support from specialist agencies it is important to assess the effectiveness of the support provided by family members, especially partners.

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[1] Placental Acute Chorioamnionitis with Fetal Inflammatory Response

[2] Rapid reviews are a multi-agency response to serious safeguarding incidents which involve gathering information from all agencies involved with a child to establish whether there is any immediate action needed to ensure their safety and the potential for practice learning.

[3] E.g. Technology, forms and other processes which support or hinder practice, organisational issues cultures, demand and workload pressures, restructuring, professional hierarchies.

[4] https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability

2.2. For pregnant women who have a learning disability it is important that GPs are pro-active in facilitating prompt booking in for antenatal care, and that they share information about their learning disability with midwifery services. People may not always want to disclose that they have a learning disability or difficulty in response to a direct question. Enquiring or reflecting about what other information they provide about where they went to school, what benefits they receive or what tasks they find difficult, or which other agencies are or have been involved in their lives, may provide clues that further enquiries with the GP or the Community Learning Disability Team might be useful. Where people with a learning disability appear to understand information provided, but then do not act on it without an understandable reason, practitioners should consider whether there might be a problem with "executive functioning" and seek specialist advice.

2.3. Practitioners would benefit from having a better understanding of the service offer from the Community Learning Disability Team. This employs specialist nurses who can support people who have a learning disability to access treatment, including arranging advocates. Non-specialist practitioners involved in this review were not confident in completing Mental Capacity Assessments and did not know who to turn to for advice. Community Learning Disability Team nurses can support practitioners by supporting the completion of mental capacity assessments and arranging "best interests" meetings[5] should a person be deemed to not have capacity. Representatives of the team can also attend key meetings in a consultative capacity (e.g. strategy meetings).

3. DETAILS OF THE FAMILY AND THE CHILD'S STORY

3.1. Family members will be referred to by their family relationship to James e.g. Mother, Father, Sibling. All family members are White British.

3.2. Some history prior to the scoping period is relevant. Mother has three older children who live with relatives due to domestic abuse from a previous partner. The first two children were subjects of private law proceedings. For the third child, social workers were involved; Mother left a mother and baby unit to go back to her abusive partner. Father has an adult son with whom he does not have contact. Records suggest he told social workers that they had only ever met once because contact had been prevented by that child's mother. Mother was diagnosed with a moderate learning disability in 2015, Father may have a "learning difficulty" or "learning disability".

3.3. Sibling was born in spring 2018. A pre-birth Child and Family assessment resulting in a Child in Need Plan was stepped down to Early Help for 6 months after the first postnatal CIN meeting held a week after his birth. Support included help to ensure correct feeding and decluttering the home.

3.4. In November 2021, after a meeting involving parents and the health visitor, the nursery school referred Sibling for a multi-disciplinary assessment by the Complex Care Team (CCT) due to concerns about global delays in his development. The parents did not identify any concerns about this and did not bring Sibling to two out of the four offered appointments with a paediatrician and a specialist speech and language therapist. During the period under review, Sibling was also not brought to ophthalmology appointments in October 2022 and January 2023. However, Sibling's immunisations were up to date.

3.5. *Paragraph redacted for publication.*

[5] A Best Interest Meeting is a multidisciplinary meeting that is arranged for a specific decision around a patient's care/treatment, when a person is deemed to lack the mental capacity to make that decision for themselves.

3.6. In October 2022 the school made a referral to the Front Door[6]; Sibling had only attended one full day since September 2022 and there were concerns about the home conditions and lack of stimulation for Sibling, as well as the parents' capacity to manage. A phone call was made to Mother who indicated that she felt Sibling was not ready for school and that she would re-register him for September 2023. This plan was accepted as Sibling was not yet of statutory school age.

3.7. Just before Christmas 2022 Mother attended midwifery services for a late booking (23 weeks gestation). The Expected Date of Delivery was early April 2023. Mother disclosed she was not caring for her three older children. She would not consent to a referral to the Front Door but did consent to the community midwife contacting the Front Door for a consultation, completed in mid-January 2023, whose outcome was that a Request for Support was not currently required, but to continue to monitor and escalate any concerns.

3.8. In early January 2023 Mother did not attend the GP for an assessment to do with her moderate learning disability. In mid-January 2023 Mother received the first of two antenatal home visits from the health visiting service. The first was conducted by a Family Partnership Practice (FPP) lead; to offer additional support. [7] Mother declined this service but accepted universal support offered by the health visiting service.

3.9. From December 2022, midwives and the consultant had concerns about Mother's anaemia (low iron levels in her blood). Delivery by Caesarean section (C section) had been identified as the most appropriate option for Mother and baby due to her obstetric history. This was not safely possible unless and until Mother's iron levels were satisfactory. Mother did not take iron supplements prescribed by the GP and she refused blood transfusions in February 2023 (twice), and March 2023 (four times). After the last refusal, which was partly associated with lack of care being available for Sibling, (Father would not allow Sibling to stay with an aunt and he was not capable of/willing to care for Sibling himself), the midwives made a referral to the Front Door. Initially, until representations were made by the hospital trust safeguarding team, social work involvement was declined due to a mistaken belief that Mother had had the transfusion she needed. The initial plan was to close the referral, until the hospital safeguarding staff provided updates which led to a decision to hold a strategy meeting.

3.10. On the fifth working day after the original referral, a strategy meeting was held. It was agreed to conduct S47 enquiries.[8] Later on the same day Mother attended hospital as she had believed the baby would then be delivered. She reluctantly accepted the recommended transfusions of blood. She was unwilling to stay overnight in preparation for having a C section the next day and Father would not encourage her to do so. Social workers sought legal advice, but no legal action is possible in respect of a child pre-birth.[9]

3.11. In the early hours of the following morning James was born at home. Father called an ambulance whose personnel attempted resuscitation and conveyed Mother and baby to hospital. James was

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[6] Front Door is shorthand for the gateway to Kent's integrated Children's Services

[7] The Family Partnership Programme is open to women from 28 weeks of pregnancy, and their families, up to a child's first birthday. The FPP aims to empower parents and help them and their family to lead a happier, healthier life. It is available to families living in Kent who have experienced difficulties such as poverty, mental health issues, family problems or domestic abuse https://family.kentcht.nhs.uk/support/your-family/health-visiting-services-for-you/family-partnership-programme/

[8] Section 47 of the Children Act 1989 is the local authority's duty to investigate where there is reasonable cause to believe a child may have suffered or be at risk of significant harm

[9] In UK law, a foetus has no rights until they are born and draw a breath by themselves, at which point they are legally recognised as an individual with separate rights. https://family.kentcht.nhs.uk/support/your-family/health-visiting-services-for-you/family-partnership-programme/

pronounced dead at the hospital. (James's death was not due to earlier refusals to have blood transfusions, as explained in the introduction).

4. THEMATIC ANALYSIS

4.1. The learning from this review was identified from information and opinions provided in the agency reports and at the practitioner event. The themes are:

- **Working with parents with a learning disability**
- **Antenatal care**
- **Making and responding to referrals**

Theme: Working with parents with a learning disability

4.2. Mencap define a learning disability[10] as *"a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people".* The nature and the extent of the support needed will vary according to the extent of the learning disability; mild, moderate, severe, or profound/multiple. Mencap have used national population statistics and public health data to estimate that approximately 2.16% of adults have a learning disability.[11] This means that non-specialist practitioners will have relatively infrequent contact with people who have a diagnosed learning disability.

4.3. Mencap states that the term learning disability is often confused with learning difficulties e.g. dyslexia. The difference is that a learning difficulty does not affect the intellect. This common confusion is evident in this case; the terms learning difficulty and learning disability are used interchangeably in several agency records. Where the term "learning disability" is used, it is either not qualified at all, or not consistently qualified; records refer to both a mild learning disability and a moderate one. No records for the period under review had any details of what impairment of functionality might involve, other than not being able to read and write.

4.4. For a range of reasons people with a learning disability often have poorer physical and mental health than other people, so it is good practice that everyone over the age of 14 who is on their GPs learning disability register has an annual health check. Practitioners told this review that GP records are the only ones that have functionality to flag the fact that a patient or service user had a learning disability. Mother's name was on the GP's learning disability register as having a "moderate" learning disability[12] and records show that Mother's last such annual health check was in 2017. It is good practice for GP practices to have a learning disability lead, who will have other duties given the small proportion of patients affected. Mother's GP told this review that a GP and the nurse with the lead for learning disability would each see the patient during an annual review. While the focus of such review is on assessing health, consideration would be given as to how people are coping, and what help and support they are receiving, or might need. This would be based on self-report or views from relatives/carers.

[10] https://www.mencap.org.uk/learning-disability-explained/what-learning-disability
[11] https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability
[12] Diagnosed learning disabilities are categorised as mild, moderate, severe or profound.

4.5. Records show that Mother's last annual health check was in 2017. While it is part of the GP contract to hold the register and do annual reviews, patients can refuse, and there is nothing a GP can do about this unless there are safeguarding implications due to not attending. Mother did not attend an appointment for a review in January 2023, nor respond to a request to make another appointment. The GP told this review that Mother had appeared to seek, and accept, health treatment for herself appropriately before being pregnant with James.

4.6. Specialist learning disability practitioners told this review that people with moderate learning disabilities would need some support from relatives or agencies in some areas of their lives. At the time, the midwives, health visitors and school staff working with Mother did not know about the support she had been offered/received previously in relation to her learning disability. This is summarised in the following paragraphs to provide context. Prior to meeting Father, Mother was living in a housing association property that offered support as well as accommodation. A care manager employed by the council made a referral to the Learning Disability Team in 2015 for a coping skills assessment in activities of daily living and support. The referral stated that Mother had had a recent "private psychology report" which highlighted she would benefit from a social comprehension and communication assessment for those agencies working with her, to understand some of the difficulties Mother has in processing information.

4.7. An assessment in 2015 by an occupational health therapist (OT) regarding shopping and preparing food concluded that Mother required support with some activities such as engaging with community activities and having a daily structure in place for activities. Mother did not feel she needed extra support. The OT report was distributed to the GP. In 2016, Mother attended one speech and language assessment appointment and then declined any further support, advising that her communication did not require any help.

4.8. Despite legal proceedings regarding the three older children and social work involvement with Sibling to assess whether parents were able to care for Sibling, there is no evidence that a specialist practitioner with knowledge of learning disability was involved in assessments and care planning at that time because the parents declined to attend appointments offered to them by the community liaison disability team. They also did not attend cognitive assessments offered to them. Arguably since the need for them to be offered had been identified, not attending should have been challenged in court, but it was not, for reasons which are not known. It may be relevant that GP records do not specify that Mother had a "moderate" learning disability until after that period. Nonetheless a specialist assessment may have still been of benefit, as a learning disability is a lifelong condition, and parents may need ongoing support to meet the changing developmental needs of children. However, the health visitor did identify that the family needed involvement at "universal plus" level which provided more contact, including review of development, and extra support if needed.

4.9. When directly asked during the scoping period whether she had a learning disability, sometimes Mother said she did not. We do not know why that was but practitioners wondered perhaps whether she felt embarrassed or worried that maybe she would be treated as more vulnerable or subject to conversations or service involvement that she did not want to have. Father's perception was that professionals saw Mother as "an easy target" and bullied her, which is why he sometimes loses his temper and swears. Practitioners told this review that both parents had negative views about statutory services, that they "take babies" or "lock people up" which was perhaps not surprising given their histories. With the benefit of hindsight there is some potential evidence of disguised compliance. For example, Mother telling the health visitor that Sibling is not currently in school, but school are supporting with this. She also told the Family Partnership Practitioner (FPP) that the late booking for antenatal care was because she had not known she was pregnant.

4.10. Practitioners working with the parents knew they had no specialist support and very limited support from extended family members. Health practitioners did reflect on the nature of Mother and Father's relationship, especially whether there were elements of Mother being coercively controlled by Father. Midwives concluded that their relationship appeared more co-dependant than abusive. It was noted that Father did the shopping. However, there is no evidence of detailed consideration by any practitioner of Father's relationship with Mother in terms of support to mitigate or otherwise her learning disability. Had health practitioners known that Mother had a diagnosis of "moderate" learning disability and known the possible implications this may have been considered.

4.11. Whilst Father was present at some antenatal appointments when he was not at work, records for all agencies show that most of the contact was with Mother. This is in line with national practice for antenatal care, on which a recent report commissioned by the national safeguarding panel commented. The recent "Myth of Invisible Men" report, published as part of a suite of national reports into non accidental deaths of babies under 12 months old[13] found that men are too frequently overlooked and are poorly engaged by universal services, such as midwives or health visitors, which is then replicated by targeted and specialist services. Records show practitioners knew very little about Father, mostly snippets that that had been revealed in conversation; an adult son he no longer had contact with, and he told the school he had been in foster care as a child. Some records refer to him having a learning difficulty or learning disability. There is no evidence this was ever explored further. Some records refer to him being "abusive" to practitioners. Midwives told this review that, when challenged, he was able to modify his language and behaviour. The date of birth he gave the police is different to the one on other agency records. It was not until after James died that it was recognised that there were two different children's social care records held for him, for reasons that are not known. A thorough search using all the available search functionality on the electronic records system should have found both records. This lack of knowledge about Father goes beyond the usual considerations of assessing him for risks and protective factors that should be done for men in close contact with vulnerable children, because of Mother's learning disability. This is because the level of her disability and previous historical assessments suggest she would need support to effectively engage with services and access treatment. Regarding pregnancy and treatment, Father was not a protective factor. However, assessing him in terms of his ability to mitigate Mother's learning disability in general might not be something those involved would recognise was necessary until and unless they realised Mother had a (moderate) learning disability, which for reasons described elsewhere we know was not the case.

4.12. A check with the GP would have revealed that Mother had a moderate learning disability. Exploration of what this might mean should have considered the historical information in the Occupational Therapist report noting Mother may need support in accessing services. It is unclear why the social worker did not contact the GP, which would have revealed she had a moderate learning disability.

4.13. A check on the Kent and Medway Care Record KMCR[14] by a health professional would have revealed that Mother had a moderate learning disability. However, there is no formal guidance on

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[13] Child Safeguarding Practice Review Panel (Sept 2021) The myth of invisible men; safeguarding children under 1 from non-accidental injury caused by male carers **and** Walters A et al (2021) Fieldwork report: National Review of Non-Accidental Injury in under 1s **both** Child Safeguarding Practice Review Panel

[14] The Kent and Medway Care Record (KMCR) provides healthcare professionals with a joined-up view of an individual's care and treatment from multiple health providers. The Kent and Medway Care Record pulls a person's information from several important areas of health and care, such as GP practices, social care, community services. https://www.kmhealthandcare.uk/your-health/kent-and-medway-care-record

when to consult the KMCR and it is not widely enough known about or used by frontline practitioners. Apart from the specialist learning disability practitioner[15], no-one involved in this review, including the GP, was aware of this. Everyone in the geographical area covered is included on the database apart from the few people who have formally chosen to opt out. The specialist learning disability practitioner told this review that if any practitioner had been wondering whether Mother might have a learning disability, if they had contacted the Learning Disability Team, a member of the duty team could have checked their records and the KMCR. Although information about Mother's involvement with the Disability Team prior to 2018 is held on paper records, the fact of it occurring was not migrated to the new electronic system for reasons that are not known, nonetheless the disability practitioner told this review that staff would check the KMCR, so the basic information that Mother had a moderate disability would be revealed and shared. Whilst it would be good practice to seek Mother's consent to contact the Learning Disability Team, this could be done without her consent if practitioners believed the impact of a possible learning disability in terms of accessing or understanding services and treatment offered could be seriously affecting her health.

4.14. For Mother there was some information known to some practitioners that should flag a need for further enquiry and/or assessment about the nature and implications of a learning disability. These were: Mother having been to a special school; being in receipt of Personal Independence Payment;[16] and a statement Mother made to a midwife that she "can't work as she has always been told she isn't intelligent enough to have a job." Records might not be available or accessible regarding benefits (the GP did not have any), schools change name (as Mother's has) and purpose and their remit in previous years might not be clear. In any case, information relating to the reasons for a statement of educational need will be out of date and focused on support to learn in school. Nonetheless, the criteria for a Personal Independence Payment for someone who does not have a physical difficulty means that even the lower rates of the mobility or personal care elements are likely to indicate a level of impairment in some aspects of daily life and across more than one of the activities. We do not know why Mother told the health visitor and midwives that she did not have a learning disability. However, whatever the reasons, especially if it included stigma, these will apply to others. Therefore, supplementary questions about "where you went to school", and "what benefits are you receiving" maybe useful when practitioners are not sure whether someone has a learning difficulty or a learning disability. Answers might then prompt further reflection on and/or enquiry about a person's abilities relevant to service involvement. In addition, not being already in receipt of specialist Learning Disability Services should not lead to assumptions that support is not required, for reasons described earlier.

Learning points; working with people who have a learning disability

- **The prevalence of diagnosed learning disability in the general population is approximately 2%. This means that non-specialist practitioners will have relatively infrequent contact with people who have a diagnosed learning disability.**
- **A proportion of non-specialist practitioners are not clear about the difference between learning difficulties and learning disabilities. These phrases are not interchangeable, and they have very different implications for how people may function, and what help they may need to access services and health treatment effectively.**

[15] This person was not involved in the case but provided expert advice to the reviewer

[16] https://www.gov.uk/pip

- **A proportion of non-specialist practitioners do not have a good understanding of how learning disabilities may impact on people, and they do not understand the implications of the different ways that learning disabilities are classified.**
- **Persons with a "moderate" learning disability are likely to need support from someone to function adequately in areas of their lives. If they are not receiving such support from specialist agencies, it is important to assess the effectiveness of the support provided by family members, especially partners.**
- **People may not always want to disclose that they have a learning disability or difficulty, in response to a direct question. Enquiring or reflecting about what other information they provide about where they went to school, what benefits they receive or what tasks they find difficult, or which other agencies are, or have been, involved in their lives may provide clues that further enquiries with the GP or the Learning Disability Team might be useful.**
- **Functionality for agency records to provide easily visible access to information that a patient or service user has a learning disability is only available for GP records.**
- **The purpose and contents of the Kent and Medway Care (health) Record is not well known by practitioners, nor specifically that it may contain information if a person has a learning disability.**
- **The benefits of consulting the Learning Disability Team who have duty staff who can be contacted during office hours.**

Theme; Antenatal care

4.15. Pregnant women in the UK are entitled to make autonomous decisions in the same way as any other person, even if healthcare professionals believe these decisions are unwise, as long as they have full mental capacity. Pregnant women can decline to engage with healthcare professionals during the antenatal, intrapartum and postnatal periods. A pregnant woman with full mental capacity may decline treatment during pregnancy, or labour, even where that might lead to death or serious harm to them or their baby.

4.16. *Paragraph redacted for publication.*

4.17. *Paragraph redacted for publication.*

4.18. *Paragraph redacted for publication.*

4.19. On attending a booking appointment with midwives in December 2022, the parents had been open about Mother's history of children not living with her and Father's previous substance misuse. The completion of a Request for Support (referral to the Front Door) was offered to the family but declined, although they agreed the midwife could contact the Front Door to gather information. A Maternity Support Form was generated by the community midwife documenting the concerns raised within the appointment and disseminated to the GP, Health Visiting Team and the community trust Safeguarding Children Team. The Safeguarding Children Team had historical information on their database that Mother potentially had a "learning disability/difficulty." The community midwife was informed of this and advised to explore this further with Mother and the lead for learning disability in the community trust. The community midwife told this review that they explored this with Mother who said that she could not read and write but that she did not have a learning disability. Because of this, and the fact that Mother appeared to understand information given to her, she did not feel it was necessary to contact the Trust learning disability lead.

4.20. The hospital trust Safeguarding Children Team routinely check all Maternity Support Forms prior to the expected date of delivery to ensure any outstanding actions are completed. These pre-birth checks were completed. The Safeguarding Children Team identified safeguarding concerns for the unborn but it was not recognised that there were the outstanding actions to explore regarding the potential "learning disability/difficulty" (sic) of Mother, and any implications for the baby, for reasons that are not known. This has been identified as a learning need for the Safeguarding Children Team and, as part of addressing that, complex cases are now reviewed weekly to ensure there is continuous oversight throughout a pregnancy.

4.21. The community midwife told this review she was mindful on how she presented information to Mother; ensuring she explained things in basic terminology. Also higher than usual contact was offered by the midwifery service for a parent with a second or subsequent pregnancy, appointments were longer, and the Group Practice Lead midwife offered to be present during the C section, as Mother knew her. Free taxis were provided for appointments at the hospital.

4.22. There was no antenatal visit from the midwifery service because such visits, suspended due to the covid pandemic, had not been re-introduced by the time when Mother was pregnant. Currently midwives offer a home visit at 16 weeks gestation, or soon after booking for those who book in later than that. Ordinarily there would only be one antenatal visit from a health visitor, but the FPP practitioner thought it would be beneficial for a second home visit by the person who would be the named health visitor. The family's need for baby equipment was an ideal opportunity to enable this.

4.23. Both health visitors identified vulnerabilities for the family from their history and the circumstances of the flat and sibling. Both had concerns about clutter in a small flat, the parents smoking in the home, and Sibling being in a nappy and pyjamas at 11:00 am. Mother declined the Family Partnership Programme; if she gave a reason it is not recorded. The second health visitor intended that the coming baby be on her targeted caseload to ensure the family received more than the standard minimum visits and support.

4.24. Neither health visitor who had visited Mother in January and February 2023 had been involved with Sibling previously and the health visiting service were no longer involved with Sibling. It is not usual practice to check siblings' records before visiting for subsequent pregnancies. Therefore, they were not aware of the concerns about their care as a young baby nor about their current development prior to their visits, including the referral to the CCCT team. They also did not know about Mother's refusal of treatment for anaemia during her current pregnancy; these concerns were just emerging.

4.25. The Family Liaison Officer (FLO) from the school told this review that she had done a lot of work alongside the parents to address the clutter as they seemed powerless to tackle it. The flat had no storage, which needed to be purchased. Outgrown toys formed some of the clutter, which the FLO successfully encouraged them to donate to the school fair. When the FPP visited in January 2022 the flat was described as cluttered but organised, the kitchen was clean and there was evidence of recent hoovering, but the parents had known that the FPP was visiting. The second health visitor had concerns about cleanliness of the kitchen. When attending after James's death, the police report described a very cluttered house which was dirty and very smoky in the communal areas, where stains on the walls suggested this was a long-term problem. Sibling's room was better. There is evidence of midwives and health visitors providing smoking cessation advice and Mother indicating she knew that smoking was a risk factor for cot death. However, both parents continued to smoke and did not appear to have recognised that a smoky atmosphere was also unhealthy for Sibling.

4.26. Antenatal care is mostly midwifery led and managed with little involvement from GPs unless they are asked to follow up issues or provide prescriptions. In this case, Mother needed prescriptions for her anaemia. In mid-February, Mother had a telephone appointment with her GP to discuss blood results which showed severe anaemia, which was also slightly worse than when she had booked in for

antenatal care. She declined to have all treatments offered for anaemia and refused to have iron supplements or a blood transfusion. If she gave a reason, it is not recorded on her GP records. The only reason she gave other practitioners during January and February 2023 was difficulty swallowing tablets, or of getting to the hospital for a transfusion because Father was working and therefore unable to provide transport. The GP told this review they believed the midwives were better placed than them to encourage Mother to take some treatment for anaemia and that they had received no further contact from the hospital about anaemia. A letter sent in the second half of March 2023 did not arrive until after the baby's death.

4.27. Midwifery and obstetric records show multiple discussions with Mother about treatment for her anaemia and the potential consequences of not having it, but also of explicit acknowledgement that it was her decision, which she perhaps could have found confusing. Staff believed she did understand the information she was being given and therefore that she had mental capacity to refuse the treatment. It may be a relevant context that midwives told this review that increasing numbers of pregnant women had firm ideas of what type of care and treatment they were willing to accept, which might not be in line with the usual model of care offered. However, in contrast to Mother, midwives told this review there was often evidence that many of these had done some research and would be able to offer some kind of rationale (appropriate or otherwise) for their decisions. However, especially with the benefit of hindsight, midwives told this review that they now wondered whether her refusal stemmed from not understanding why she would need this treatment for this pregnancy when she had not for the four previous ones.

4.28. The Mental Capacity Act (MCA) 2005 has five key principles - the presumption of capacity; that support should be provided to make decisions; that people have the right to make what others might consider to be "unwise" decisions; that anything done by others must be in the person's best interests; and that necessary action must be the least restrictive possible in the circumstances. The MCA says that a person is unable to make their own decision if they cannot do one or more of the following four things: understand information given to them; retain that information long enough to be able to make the decision; weigh up the information available to make the decision; and communicate their decision in some way. There is no evidence that consideration was given to undertaking a formal Mental Capacity Assessment with Mother, all practitioners believed that she understood the information she was being given and was therefore making "unwise decisions" not to have the treatment for her iron levels. Even had midwives known that Mother had a moderate learning disability this would not necessarily mean that she did not have capacity. However, it would have made it more likely that they would have considered the need for advice from a learning disability specialist.

4.29. There are some indications, which are much more visible with the benefit of hindsight, that Mother may have needed an assessment for "executive capacity". 'Executive function' involves skills such as planning, motivation, multi-tasking, flexible thinking, monitoring performance, memory of conversations beyond being able to repeat back what has just been said, self-awareness, and detecting and correcting mistakes. People need these executive function skills for day to day activities: to cook a meal; follow a conversation; interact with others; work; study; and plan their day, for example. Problems with executive function might be suspected if someone seems, in theory, to appreciate and understand their situation, but is then struggling to elicit the relevant bits of information and use them in the right context. They may also struggle to act upon or execute a decision. This is different to unwise decision making, where the person is fully aware of the facts presented but consciously disregarding or giving less weight to all or some relevant to the decision but would be able to articulate their reasoning in a logical way. Assessments for a deficit in executive

function are a particularly complex aspect of mental capacity assessments, not least because people with executive function impairment can present very well and mask their deficits.[17]

4.30. A lack in executive capacity could explain some of the behaviour that midwives found very puzzling. For example, when she had appeared to agree to have a blood transfusion on two occasions and then changed her mind in the short time it took for the midwife to fetch the necessary equipment. Also, that her reasons for not having blood transfusions were of a kind that most people would have managed to overcome, especially as the midwives offered practical solutions to most of them, which were always rejected without satisfactory reasons.

4.31. All practitioners that were involved with Mother indicated that they would not feel confident to undertake a formal Mental Capacity Assessment, and most did not know who they could turn to for advice and support. The health visiting service no longer has a learning disability specialist health visitor. There is a Learning Disability Nurse situated within the hospital trust Safeguarding Team who has provided support for staff when caring for patients with a learning disability/difficulty which includes easy read documents, hospital passports and a distress tool. The hospital trust recognises that assessing parental mental capacity in pregnancy is extremely complex and support for staff needs to be prioritised. As part of the learning from this case, a task and finish group has been created to develop a toolkit to support staff caring for these vulnerable mothers; it is intended the first draft will be available in April 2024. The hospital trust Safeguarding Team deliver level three training to staff working within the trust which includes enhanced teaching about mental capacity, and the Trust Mental Capacity Lead is developing workshops from January 2024 for all staff to attend to help them gain increased knowledge and understanding of mental capacity and the Mental Capacity Act 2005. Complex maternity cases, where there are concerns surrounding capacity or where significant learning disability/difficulties are identified, have been discussed weekly during the Safeguarding Children Team case management meetings. Since these meetings started in September 2023 there have been no cases identified at a late stage in pregnancy.

4.32. Whilst the Trust Learning Disability Team only gets directly involved, as opposed to providing information and advice, with people who have a diagnosed moderate/severe or profound learning disability, they accept calls when practitioners are uncertain whether someone has a learning disability, as they have access to information to identify those people that do. Only one of the practitioners in this case had ever had occasion to call the Trust Learning Disability Team, which is perhaps unsurprising given the small percentage of the population affected. The Community Learning Disability Team is multi-disciplinary and employs specialist nurses who can support people who have a learning disability to access treatment. Had practitioners contacted the team they would have discovered that the service offer for Mother could have included accompanying her to appointments, assessment of her communication skills and ability to understand and retain information and/or arrange an advocate if appropriate. If the nurses identified that a mental capacity assessment was necessary, they could have completed that, and then, for anyone who lacks capacity, arranged a best interests' meeting(s) for all practitioners involved to consider appropriate action.

4.33. This review was told that referrals to the Learning Disability Team are screened within one working day and that twice a week all new referrals are discussed at a multi-disciplinary team meeting. If necessary, the service can respond quite promptly, for a recent referral a worker became involved within a week. Mother's need for treatment for the anaemia, the urgency and the invasiveness and

[17] https://www.lancashiresafeguarding.org.uk/media/19288/executive-functioning-grab-sheet-mca-guidance_v10_apr2021.pdf

inconvenience of it needing to be in the form of transfusions increased significantly as her due date approached, especially as the plan was for a C section, which could not safely go ahead unless her blood iron levels were satisfactory. As is detailed in the section on learning disability, the specialist community Learning Disability Team can provide support at quite short notice, although it is much preferable to have time to build a relationship with the person and liaise with others involved and conduct assessments. Having said that the local manager of the Learning Disability Team told this review that for patients in hospital, a member of the team has made a visit on the same day. The acute liaison disability nurse located within the hospital runs a weekly discussion regarding every patient with a learning disability admitted to the hospital via A&E or their GP. Even had Mother's moderate leaning disability been known, this would not have included her as she was attending the maternity ward on an outpatient basis. However, since this case the trust Safeguarding Team has started holding weekly case review discussions about complex maternity cases; these have included cases where there are concerns about the adult or baby due to a Mother's learning disability. In addition, this review was told that the maternity electronic recording system has capacity to record when a mother has a learning disability and that this will be implemented in April 2024 as part of the toolkit referred to earlier

4.34. In some parts of Kent, multi-agency midwifery hub meetings occur to discuss concerns about and support for vulnerable pregnant women (with their consent) including whether a referral might be needed to the Front Door. There is no Terms of Reference of formal threshold for referral and meetings vary from fortnightly to monthly across the areas. They are organised by one of the hospital trusts and chaired by a safeguarding midwifery specialist. Invites go to social care, community midwives, FPP and the Health Visiting Service. Occasionally police or probation attend. There has been no formal evaluation of these hubs but anecdotal evidence suggests that they are valued by participating practitioners.

Summary of learning: Antenatal care

- ***Paragraph redacted for publication.***
- **For pregnant women who have a learning disability the importance of GPs being pro-active in facilitating prompt booking in for antenatal care, and sharing information about their learning disability with midwifery services.**
- **Poor care received by a sibling is likely to be predictive of the care a further child will receive.**
- **Parents' struggles with the care of one child may be compounded by the arrival of another.**
- **Where people with a learning disability appear to understand information provided but then do not act on it without an understandable reason, practitioners should consider whether there might be a problem with "executive functioning" and seek specialist advice.**
- **Practitioners without specialist knowledge of learning disability are not confident in completing Mental Capacity Assessments and do not know who to turn to for advice.**
- **Practitioners would benefit from having a better understanding of the service offer from the Learning Disability Team who employ specialist nurses who can support people who have a learning disability to access treatment, including arranging advocates, and support practitioners by completing mental capacity assessments and arranging best interest meetings, should a person be deemed not to have capacity.**

See recommendation B

Theme: Making and responding to referrals to the Front Door;

4.35. Sibling commenced nursery in September 2020 and moved to the reception class in the school in September 2022. Sibling had a long history of poor attendance at nursery. Records for June 2021 indicate the health visitor and nursery staff sharing the 'same niggling concerns' regarding the family. This led to a conversation with local Early Help Open Access and a decision was made to try and engage the family in support as it was not felt at this time threshold was met for a referral to the Front Door. In this record it was recognised that mother "does not accept help readily" and "has a very low IQ and learning difficulties." The health visitor made an unsuccessful attempt to contact the parents three months later. Family Liaison Officer records suggest the Health Visitor then closed the family on the basis that the nursery would continue to monitor.

4.36. In June 2022, records of an initial pre-school admission home visit by the Family Liaison Officer describe home conditions as cluttered and chaotic. Sibling was observed to have delayed speech, a lack of routine and boundaries and Mother was observed to speak to him in a 'monotone instructional tone of voice' and communication appeared to 'lack age-appropriate warmth.' At this visit, Mother declined an offer for a referral to support agency Homestart[18] and 'appeared guarded.' She agreed to continued visits from the Family Liaison Officer. Records indicated concerns regarding Mother's ability to respond appropriately to Sibling, both physically and emotionally. This included not recognising the dangers involved when Sibling put toys in a microwave and turned it on, which set the toy alight. The Family Liaison Officer intervened due to concerns that Mother would not.

4.37. In October 2022 the Headteacher made a referral to the Front Door regarding attendance and concerns about Mother's capacity to parent and organise getting Sibling to school. Sibling's speech was described as poor, he still had a dummy and was not toilet trained, and parents had declined help with this. The referral mentioned that staff had offered options to the parents in terms of timetable changes and support, which were declined. School staff told this review that the reasons given for non-attendance were often inappropriate, e.g. he didn't wake up on time or he doesn't want to come.

4.38. School staff were so concerned that although they informed the parents about the referral, they made it without their consent, i.e. they perceived that they were making a safeguarding referral. However, Front Door records show a belief that the school's primary concerns were about lack of attendance. A phone call was made by a social worker to Mother who indicated that she felt Sibling was not ready for school and that she would re-register him for September 2023. This plan was accepted as Sibling was not yet of statutory school age. Mother declined an offer of Early Help support, but indicated she might accept it should this be needed when Sibling was of statutory school age. She was given the Front Door contact number and was sign posted to the GP and children's centre for support with Sibling's speech delay and toilet training. The school had not mentioned the referral to the CCT. Staff told this review this was because they thought his Special Education Needs were not relevant to the purpose of the referral. However, this meant the social worker was not aware that the level of concerns about Sibling's developmental delay required more support than the school could offer. They were not able to discuss this with Mother nor enquire regarding progress with this, when they might have then discovered the missed appointments.

4.39. On reflection, school staff recognise that perhaps more specific details about the impact on Sibling and the lack of progress, despite the involvement of the Family Liaison Officer might have prompted

[18] https://www.home-start.org.uk/ is a charity that recruits trains and support volunteers to provide support and friendship to parents in their own home

a recognition that parenting capacity needed to be assessed. Social workers told this review that explicitly referencing the threshold criteria[19] assists them in identifying when a social worker needs to be involved. The criteria include examples of concerns where a social worker would become involved and tips about making an effective referral. Recent local focus group activity co-ordinated by the Partnership has identified that in general there appears to be a good understanding of the thresholds. However, practitioners told this review that not everyone was confident and skilled in making an effective referral, and sometimes there were systemic barriers. For example, the school making a referral was not helped by notes of the Family Liaison Officer's visits being kept in a separate file to Sibling's main school safeguarding file. This is being addressed because of this review. The Family Liaison Officer notes provide a detailed picture of the home environment and concerns about parenting; more evocative details such as the microwave incident that were not included in the referral. In addition, the referral was made by email rather than via the Front Door portal, and the health visitor was no longer involved from whom either party could seek an additional view. There was no discussion between the Front Door Service and the school, which might have been helpful to reflect on Mother's response to the phone call from the social worker together and clarified the level of the school's concerns about parenting. School staff have reflected that they could have challenged the outcome of the referral and in future similar circumstances would do so. They also felt they could have provided more information about the amount and nature of the support the Family Liaison Officer had provided which included "doing alongside" activities (e.g. to organise and get rid of clutter in the flat) rather than being limited to information and advice. This latter point is important because a recently published Ofsted summary of the findings of joint inspections on "Early Help" in five local authority areas carried out between December 2022 and March 2023[20] indicated that school leaders had reported "they were too often working in isolation to keep vulnerable children physically, socially and emotionally safe." In addition, a recent Rapid Review of a local case described how the improvement in a child's circumstances had been misattributed to the mother because the social worker was not aware of the huge amount of support being provided by the school.

4.40. The Family Liaison Officer continued to make home visits to promote better routines and encourage school attendance with little success. Up to November 2022, Sibling only attended on seven occasions. After the referral in October 2022, Mother told the Family Liaison Officer she knew Sibling did not have to attend school. The school Attendance Officer was also visiting because school staff were worried about the impact of Sibling's non-attendance. Their notes in November 2022 refer to a further offer of referral to Early Help for support, which was again declined by Mother. Whilst school staff continued to have concerns about the environment Sibling was living in and Mother's capacity to meet his needs, they did not have new information that made them feel able to make a further (safeguarding) referral.

4.41. In early January 2023 during a telephone discussion about Sibling's non-attendance, Mother informed the Attendance Officer that she was 26 weeks pregnant and that the baby was due in April. School staff have reflected that this could have prompted them to review what was known about the family, with further consideration being given to making another referral to the Front Door.

[19] https://www.kscmp.org.uk/guidance/kent-support-levels-guidance

[20] https://www.gov.uk/government/publications/the-multi-agency-response-to-children-and-families-who-need-help/the-multi-agency-response-to-children-and-families-who-need-help

4.42. In mid-January 2023 the named midwife[21] contacted the Front Door for a consultation as agreed with Mother at her booking in appointment. The FPP health visitor had recently contacted the midwife to share information about the family. Since Mother had declined the involvement of the FPP, who had also completed the standard antenatal visit which meant there would be no further routine involvement of a health visitor until after the baby was born, it was agreed that midwifery would take the lead on any safeguarding issues. There is no record of the midwife contact in the Front Door's records. This review was told that the Front Door keep a record of the consultation in the "consultation folder" and should inform the practitioner making contact to keep a record of the discussion and that information will not go on a child's file because of the lack of consent and the fact the consultation discussion may anonymise the case. There is no multi-agency policy and procedure regarding this practice, and it was not well known amongst practitioners involved in this review that consultations were not recorded by the Front Door. Therefore, it is not known what consideration the Front Door gave to the family history, or whether consent should have been sought or overridden to contact school for information about Sibling, or whether a pre-birth assessment was considered. According to midwifery records the outcome of the consultation was that a Request for Support (referral) was not currently required, but for the midwives to continue to monitor and escalate any concerns.

4.43. Local threshold criteria[22]indicate that family circumstances reached the point when social work involvement should be offered (level 3) either as child in need or via S47 enquiries when an "unborn child was being placed at risk, previous children/siblings had been removed." Whilst the former criteria could be considered not to apply at this stage, the latter did. However, practitioners told this review the fact that the parents were caring for Sibling might have been considered to have overridden that. Whilst this would be an understandable point of view, it may not sufficiently consider that as a baby, this had been with additional support, including input regarding feeding to overcome faltering growth, and that circumstances had changed now that parents would have two children. Other threshold criteria for social work involvement include "parental learning or physical disability impacting upon child's welfare and safety". However, it was not clear to practitioners providing antenatal care at the time that Mother had a moderate learning disability. Social workers would have had access to information that Mother "had a learning disability" due to the Child and Family Assessment completed in 2018. In addition, local guidance for pre-birth assessments draws attention to relevant case law, that where pre-birth involvement is a result of the mother's learning disabilities causing uncertainty as to her ability to meet the needs of the child once born, the court of appeal stressed the importance of effective planning during the pregnancy for the baby's arrival, and of taking adequate steps to ensure the mother understands what is happening and is able to present her case.[23] In other words, the importance of completing assessments early, and offering support early, if there is any doubt about a pregnant mother with a learning disability being able to care for a child. Nonetheless, even had a pre-birth assessment been considered appropriate at the time, there would likely not have been sufficient grounds to pursue this unless the parents consented.

4.44. Because of Mother's obstetric history it had always been planned to deliver the baby by C section which would usually be scheduled for about a week before the birth of the baby, i.e. just before the end of March 2023. Midwives had become increasingly concerned about Mother's pregnancy; as well as not accepting treatment for anaemia, a scan in mid-February 2023 had identified the baby

[21] The midwifery service comprises of community midwives and acute midwives who work in the hospital. The named (community) midwife takes the lead on behalf of the service.

[22]https://www.medwayscp.org.uk/mscb/downloads/download/122/mscp-threshold-guidance-2021

[23] Parents with Learning Disabilities (trixonline.co.uk)

was small and not growing as expected. The accumulation of concerns were discussed in a supervision between the named community midwife and their team leader towards the end of March 2023. The outcome was a consultation with the community trust safeguarding staff who advised that a Request for Support without parental consent should be submitted. This was done within two days of the supervision, and the parents were informed about it. The referral included that Sibling was still in a nappy and using a dummy aged 4 years, and expressed concerns about how Mother would cope with two children.

Following the referral being made, contact was first made with both parents via a telephone call two working days later by a social worker in the Front Door Service**.** The call to parents was made within the three working days timescale, although ideally, given there was a weekend in between, and the very late stage of pregnancy, it would have been preferable to call them sooner. At the time of the phone call, Mother and Father reported they were at the hospital for Mother to have a blood transfusion. Mother and Father did not identify any support needs and they did not consent for any further support.

4.45. Checks with the school established that in early March 2023, both parents had met with the School Attendance Officer and agreed that Sibling would commence a part-time timetable from 17th April 2023. The school agreed to monitor and agreed that if Sibling did not start once he was of statutory age, they would contact Children's Services. There is no record of any discussions about Sibling's development or concerns about parenting. The Front Door Service undertook a police check on the 27th March 2023, which did not identify any current concerns in respect of domestic abuse. Accordingly, the social worker felt reassured that plans in place appeared sufficient and the midwifery team were informed by email the following day that there would be no further action. There is no reference in the social work record of the response to the referral or any consideration of whether there might be a need to find out more about the nature of Mother having a "learning disability". It is not standard practice to contact GPs for information about parents unless there is an obvious reason to do so, and if the social worker had had time to review previous records, a logical starting place would have been the Child and Family Assessment in 2018. In the summary analysis this does refer to Mother having a "learning disability" which might affect her parenting but also that with support from Father, family members, and a CIN plan, good enough care could be provided for Sibling as a baby. This wording and level of detail would not have prompted the social worker to enquire further.

4.46. The outcome of the referral was sent by email on the fourth working day after receiving it, (just outside the within three working day local standards set for the Front Door to respond for Requests for Support). In response, a member of the hospital trust safeguarding team contacted the Front Door to describe concerns that had arisen since the original referral had been made. These were that; Mother had not yet had any blood transfusions, refusing them on two days and not attending at all on a third day; that she was not prioritising the health of her baby; and that the potential impact on her own physical and mental health of continuing to refuse treatment could affect her ability to care for both children. The information from the hospital described the reasons the parents gave for not having the transfusions which included Sibling being bored in the hospital. Staff suggestions of providing toys from another ward, or playing on a phone, or going for a walk in the grounds with his father, or being cared for by his aunt, were all rejected by the parents. Also, on that very morning Mother had arrived for the transfusion but then left because, she said, Father was not able to care for Sibling as he could not change a soiled nappy.

4.47. In response, a social worker from the Front Door contacted the parents again, by telephone. Only Father was willing to talk to the social worker. He explained that Mother had not had the transfusion yesterday as the 'hospital took so long that they decided to leave.' A family member was identified

to care for Sibling, however, they were unable to do so for the length of time required for the transfusion and Father told the social worker that he could not care for Sibling without Mother as he was unable to change nappies. Father was asked if they would like any support in relation to this and they were both clear that they did not consent for this to happen. The social worker repeated the medical concerns to Father and that the baby was deemed to be at risk of significant harm because of not having the treatment. Father stated that they could not force Mother to have the treatment and he did not think anything serious would happen.

4.48. Subsequently the social worker phoned the safeguarding staff at the hospital who confirmed that Mother was too anaemic for a C-section and there were risks associated with the parents' plan to give birth naturally. The social worker indicated that as the parents would not consent to receiving any social work involvement then a strategy meeting would be held. The strategy meeting was held the following morning. Local multi-agency safeguarding procedures indicate that strategy meetings should be held within 24 hours**.** This review was told that decisions about timing of individual strategy meetings were made based on urgency and capacity of participants to attend**.** The reasons for the timing of the strategy meeting in this case are not known but given the likely imminence of the birth and the increasing level of concern it would have been more ideal if the meeting could have been held the previous afternoon.

4.49. The community midwifery group practice lead attended the strategy meeting as the community midwife was unable to attend, and neither was a member from the hospital trust safeguarding team. There was no representation from the health visiting service, who were not aware of the meeting until after it had happened. This could have been due to a misunderstanding about the role of the Front Door health representative who can access the health visiting records but who is not responsible for liaising with the health visitor before or after the meeting. This review was told that health records indicate that information shared by the Front Door health representative with the chair of the strategy meeting was that Mother had a "moderate learning disability" as advised on the KMCR record. This is not recorded on the child's record and the record of the strategy meeting refers to "learning difficulties."

4.50. Strategy discussion notes suggest that the school information did not fully reflect the extent of the support offered to the family by the school, nor did it fully describe the observations of the home conditions and concerns regarding parenting. Nonetheless, the school told this review they felt relieved concerns about Sibling had been recognised during the meeting. Information shared by attendees about parents learning needs varied from learning difficulties affecting reading and writing, to Mother having a "mild learning disability," to both parents having "learning disabilities." The specialist learning disability representative told this review that had this lack of certainty been recognised they could have attended the strategy meeting. This would have brought more clarity about the diagnosis of a moderate learning disability. In addition, the presence of a specialist who understood what this might mean would have prompted a discussion about the parents' communication needs, the extent to which they really understood the medical concerns and how best to engage and support them, which practitioners should be involved in this, how and when. It might also have led to an outcome of undertaking a formal mental capacity assessment. Local multi-agency safeguarding procedures for convening strategy meetings[24] state that alongside social workers, police, health and the referring agency attendees as a minimum, consideration should be given to the need to include a professional with expertise in particular cases of complex forms of

[24] https://www.proceduresonline.com/kentandmedway/chapters/p_strat_discus.html

alleged abuse and neglect. This guidance could usefully be expanded to mention a relevant specialist where it is suspected that a parent may have a learning disability.

4.51. The outcome of the strategy meeting was for a single agency section 47 enquiry. During the rest of the day social workers had further conversations with midwifery staff and Father. The parents had arrived that day believing Mother would be having the C section. Midwives understood that the obstetrician wanted to do the operation as soon as possible, but the anaesthetist felt the risks were too high due to the anaemia. Initially acute midwifery staff had indicated that Mother would be staying in hospital until after she had had the baby. Because of this, and because Father told social workers that Sibling was with a family member, and he and Mother were too busy for a visit that day, the social work plan was to try to arrange to see Father at home later that day, to review home conditions. However, during the afternoon, having almost completed receiving the first of two units of blood required, Mother indicated she wanted to go home. Mother was persuaded to accept transfusion of a second unit of blood by midwives, whose records indicate it was agreed she could go home that evening on the understanding she would return at 7am the following morning. Blood transfusions take a few hours. As it was unclear at the end of the working day what time the parents would get home, the social work plan was to visit the following day. Until the strategy meeting after the baby was born, records show that social workers had believed that Mother had (formally) discharged herself against medical advice. It is unclear how this misunderstanding arose, whilst hospital staff would have preferred her to stay overnight because she had not previously returned for appointments, there was no medical reason why she should not go home.

4.52. The overall delays between the receipt of the referral and the first conversation with the parents and communication of the outcome to the hospital, and between the challenge to a no further action outcome and the strategy meeting, reduced opportunities for a joint discussion with the parents by a social worker and a midwife.

4.53. Referrals from school and the midwives were both submitted electronically. This has advantages and disadvantages. Benefits are that referrers collect and express their concerns in a thought through way, and the Front Door staff can manage a high volume of contacts and the pace of their workload and exercise their professional judgement to identify what should be a small proportion of referrals which might need a direct conversation with the referrer. However, when social workers do respond to referrals without having a conversation with the referrer, there can be a risk that important details, which would have been elicited during a conversation, might be missed, or that information is not understood in the way that the referrer intended. It may also increase the risks of early evidence bias;[25] when a first summing up of a situation strongly influences the analysis of subsequent or new information. It is therefore important that Front Door staff always consider whether a phone call with the referrer would be helpful. Both referrers thought they were making a safeguarding referral, whilst Front door staff may not agree with that characterisation even after speaking to referrers, this view of the referrers was not understood by social workers at the time. Whilst it would have been beneficial for the Front Door to contact the hospital to confirm whether Mother had had a blood transfusion before deciding the referral should be closed, the reasons for the intended closure of the midwifery referral were explained well in the email sent by the social worker and this enabled the safeguarding team in the hospital trust to challenge this by providing an update and further information as previously described.

[25] Broadhurst et al (2010) 10 pitfalls in assessment and how to avoid them; what research tells us NSPCC

Summary of learning: Making and responding to referrals

- **Awareness needs to be raised amongst practitioners that the Front Door cannot record consultation on a child's file without consent.**
- **Reference to the threshold guidance can assist in making referrals to the Front Door more effective.**
- **When parents disclose a pregnancy in circumstances where there are concerns about older siblings, the practitioner should review what is known to consider whether a Request for Support might be necessary.**
- **The potential for involving a representative from the Community/Trust Learning Disability Team in strategy meetings.**
- **When receiving written referrals, the importance of Front Door staff continuing to consider whether a phone call with a referrer would be helpful.**
- **When referrers are notified of outcomes they were not expecting, especially if these are no further action, the importance of challenging this in line with the local escalation and professional challenge policy.**[26]

5. PARENTS' COMMENTS

5.1. The parents provided information via an intermediary.[27] Regarding their experience of what could have been better, the couple were very clear that they felt dismissed and unimportant. They said this perception was reinforced, for example, when they were asked to move to free up the bed for another prioritised pregnancy. They described everyone around them as being extremely busy, which they felt affected communication with them. They said that when they were engaged with, they felt that no one knew anything about them or their history. Ultimately, the couple interpreted the lack of attention and communication as a sign that their situation and they themselves were not important.

6. POSITIVE PRACTICE

When undertaking a review, it is important to also consider the kind of positive practice that might have broader applicability to protecting or supporting other children and families. Examples of positive practice in this case include;

Protective and supportive actions by practitioners
Detailed recording of comprehensive discussion with Mother by the Family Partnership practitioner was a good briefing for the health visitor.
Family Partnership practitioner and health visitor enquired about why Sibling was not in school and noted potential developmental delay and arranged for the provision of a Moses basket which the health visitor delivered to give opportunity for contact and further assessment.
Nursery/school records regarding Sibling identified persistent efforts to encourage attendance, and communication between the nursery and school when Sibling transferred.
Midwifery records held a an easily accessible chronology.

[26] Kent-Escalation-and-Professional-Challenge-Policy-May-2024.pdf (kscmp.org.uk)

[27] Unfortunately, despite parental engagement being a consideration from the beginning of this review it was possible to obtain any feedback until the very end, after the authors contact with practitioners had concluded.

Midwifery services discussed this case in supervision, consulted the hospital safeguarding team after the booking appointment, and gained Mother's consent to consult with children's social care.
The involvement of the hospital safeguarding team in advising and supporting midwives and in challenging the Front Door NFA decision when Mother would not accept blood transfusion.
Hospital midwives sought advice from Independent Domestic Violence Advisors IDVAs.
Midwives offered a range of suggestions and support to amuse Sibling while Mother had the transfusions(s); toys, Father take for a walk, use of phone, and care by a relative.
Parents were enabled to spend time with their baby after he had died. Photographs and a memory box were given to parents. Counselling was offered to Mother but declined. Parents left the ward with a plan for community maternity services to offer support.
The Consultant Obstetrician contacted labour ward at the end of March despite not being at work that day to ensure Mother had attended for her blood transfusion as they were significantly concerned about Mother's post-natal safety due to her low haemoglobin which could result in a risk to her life.
During the antenatal appointments midwives identified that Sibling was not in education, wearing nappies and using a dummy at almost 5 years of age. Staff addressed this with Mother and escalated their concerns to the Safeguarding Children Team. Staff also offered support to Mother through the completion of a Request for Support.
Liaison between Family Partnership Lead, health visitor, and midwifery services and agreement that the latter will contact children's services and lead on safeguarding.
Health visitor recognised vulnerabilities and intended to offer targeted level of service.
Health visitors and midwives enquired about/considered domestic abuse and advised regarding risks of smoking.
After the strategy meeting the social worker compiled a pre-birth plan and emailed it to the hospital safeguarding team. The pre-birth plan identifies that a discharge planning meeting needed to take place once baby was born and before they could return home.

7. CONCLUSION

7.1. As noted throughout the report, and in the section above, there was evidence of good practice from all agencies who were involved. However, there is also learning in this case about how to improve services during pregnancy for women with a moderate learning disability. Support from the GP to enable Mother to have had earlier access to antenatal care would have maximised the time available for midwives to build a rapport with her. Had anyone recognised possible signs of Mother having a learning disability or clarified the inconsistent language about her learning needs in the records and identified that she had been diagnosed with a moderate learning disability, midwives would have been better placed to consider whether they needed to seek specialist help regarding her understanding and accepting recommended treatment when difficulties about this arose. However, whilst this meant the treatment she received in pregnancy was not optimal, it was other risks associated with the pregnancy which resulted in the death of James. Action has or will be taken by agencies involved in this review to improve services as a result of this case.

8. RECOMMENDATIONS

That Kent Safeguarding Children Multi-agency Partnership (KSCMP) should

A) Ensure better local arrangements to provide support and assess risk for parents who have a learning disability by developing a multi-agency action plan which considers all the learning from this review and specifically produces the following outcomes described below. The group developing the action plan should include at least one representative with a specialist knowledge of learning disability

   Required outcomes;

   I. That all practitioners understand the difference between learning difficulties and learning disabilities and are confident about asking questions/recognising information which might indicate someone has a learning disability even if they state this is not the case.

   II. That all practitioners understand that there are different degrees and aspects of learning disability; that people with a moderate learning disability are likely to need support from someone to function adequately in areas of their lives and the concept of "executive functioning."

   III. That practitioners know how to find out if a person has a diagnosis of a learning disability and that they know who to turn to if they want a reflective discussion about this or need advice and support about Mental Capacity Assessments and Best interest Meetings.

B) Request Kent and Medway Integrated Care Board lead a multi-agency evaluation of the maternity hubs, which includes consideration of the appropriateness and feasibility of establishing them across the whole county.

C) Request the ICB to ensure the learning from this review is disseminated amongst all local GP practices. The ICB should promote GPs i) offering proactive support to pregnant women who have a learning disability to facilitate prompt booking in for antenatal care and sharing information about their learning disability with midwifery services and ii) entering information on the patient record, especially regarding patients with a diagnosed learning disability, so that it also appears on the KMCR.

D) Seek assurance from each agency involved in this review that single agency learning points have been identified and action has been/or is being taken to address and disseminate them.

E) Ensure Learning from this review is disseminated to Kent schools via the Education Safeguarding sub-group.