

### **CHILD SAFEGUARDING PRACTICE REVIEW**

## Child F

Date agreed by the Executive Group for HCYPSP: 07 February 2022

**Lead Reviewer: Karen Perry** 

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#### INTRODUCTION

- 1.1. This Child Safeguarding Practice Review is in respect of Child F who died in hospital age 6 months as a result of head, spinal and eye injuries as well as healing fractures and a previous brain injury caused a few days earlier. His father was convicted of murder. Evidence presented in court indicated Mother knew about the earlier injuries; she was convicted of causing or allowing his death.
- 1.2. All learning points are listed in section 4, at the end of each of the four themes: response to babies born with health conditions; communication with parents whose first language is not English and consideration of cultural background; how practitioners and agencies worked together, making and responding to referrals; the arrangements to safeguard and promote the wellbeing of Child F and his sibling. What follows is a summary of the most significant learning from this review.
- 1.3. It is important to consider the impact on parents and any siblings of an unexpected diagnosis of a serious health condition shortly after birth. Where children remain in hospital for prolonged periods parents can face significant challenges due to additional costs, e.g. travel, and practical problems caring for siblings. A child who has been in hospital for 3 months or more is entitled to an assessment of their needs by a social worker, while parents who care for a disabled child are entitled to a carer needs assessment, conducted by an officer from the council's Disabled Children's Service.
- 1.4. It is important to consider parents' cultural backgrounds; whether and how they might affect their understanding and response to their child's diagnosis and their expectations of treatment. When using interpreters there are benefits in using the same one for parents who need long term support, and practitioners would welcome training about establishing effective working relationships with interpreters. It is helpful to provide information in parents' first language, which they can refer back to independently.
- 1.5. When a child is disabled signs of abuse can be masked or misinterpreted due to assumptions about ongoing health conditions or impairments. It is important to recognise the potential for some Acute Life-Threatening Events (ALTEs) to later turn out to be due to abuse.
- 1.6. Halton Children and Young People Safeguarding Partnership (HCYPSP) will ensure that learning is widely disseminated locally via practitioner learning events and a seven step guide that will be distributed directly to practitioners as well as being available on the partnership website. 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 Child Safeguarding Practice Review takes into account multi-agency involvement from February 2020 (earliest contact with agencies due to pregnancy until beginning of March 2021 (2 weeks after Child F presented for treatment for the injuries which precipitated this review).
- 1.7. Halton Children and Young People Safeguarding Partnership (HCYPSP) 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. Practitioners were asked to contribute to most single agency reports and to attend two practitioners' meetings led by the author of this report, who is independent of this case and all agencies involved with the family. Family members were also offered the opportunity to speak to the lead reviewer. Both parents agreed to do so; their comments are included in section 5.

#### 2. DETAILS OF THE FAMILY AND CASE CONTEXT

2.1. Family members will be referred to by their family relationship to Child F e.g. Mother, Father, Sibling etc. The family are of European heritage, English is not their first language; they arrived in the UK

in 2019. Halton has small numbers of people with a BAME¹ heritage. Child F had Down's Syndrome,² which required intervention for a cardiac anomaly and specialist support with feeding. At the time of the injuries that prompted this review Child F was living with Mother, Father and Sibling. Mother and Father were experienced parents and there had been no concerns about their care of Sibling. Apart from attendance at various outpatient appointments, the main additional care Child F needed was more frequent feeding through a PEG³. He has been described by practitioners as achieving his developmental milestones and been observed smiling, babbling and engaging with his parents.

#### 3. THE CHILD'S STORY

- 3.1. Child F was born in August 2020 at 37 weeks gestation, having received appropriate ante-natal care. At birth Child F had a cardiac abnormality; he was transferred to the Paediatric Intensive Care Unit (PICU) in the local regional specialist children's hospital the same day and placed on a ventilator. Mother was discharged home. Down's Syndrome was also suspected; this was unexpected as the results of the relevant blood test during pregnancy had a shown a lower risk of 1:160. The diagnosis of Down's Syndrome was confirmed at the regional specialist hospital on the day of admission.
- 3.2. After 1 month in the specialist hospital, in September 2020, Child F was transferred to the local hospital with a nasogastric feeding tube<sup>4</sup> in place. In December 2020, because of concerns about the risk of aspiration<sup>5</sup> through the nasogastric tube, Child F returned briefly to the specialist hospital for a PEG to be fitted as a safer method of feeding him. After a multi-disciplinary meeting involving relevant health practitioners, just before Christmas 2020, Child F was discharged home to the care of his parents. Planned input from agencies involved temporary community nursing involvement to support and monitor feeding plus ongoing support from the health visitor plus a range of outpatient appointments over time.<sup>6</sup>
- 3.3. Prior to Child F's discharge from hospital, the health visitor had made a referral to the Integrated Contact And Referral Team (ICART)<sup>7</sup> towards the end of November 2020. After screening, the family was referred to Children's Centre for allocation of an Early Help Officer to complete a Multi-Agency Plan (MAP)<sup>8</sup> with the family. This was to incorporate home safety assessment, carers centre support, and referral to the Citizens Advice Bureau (CAB) for advice on finance/benefits. An Early Help Officer became involved in mid-January 2021, she made several enquiries about potential support for the family and completed the MAP in consultation with the health visitor.
- 3.4. In mid-February 2021, an ambulance was called by relative due to Child F having "collapsed" at home; before arriving at the local hospital paramedics rang this through as a cardiac arrest and reported the incident to the police. As there was no clear medical cause for the collapse, the Acute Life-Threatening Event (ALTE) protocol was initiated by the local hospital. Child F was transferred to the PICU at the specialist hospital where a CT scan revealed the non-accidental head injuries that prompted this review.

<sup>2</sup> Down's Syndrome, which is also know as Trisomy 21, is a genetic condition that occurs by chance, and which is associated with a range of health conditions and some level of intellectual disability

<sup>4</sup> Nastrogastric feeding is where a narrow feeding tube is placed through the nose down into the stomach

<sup>&</sup>lt;sup>1</sup> BAME Black and Minority Ethnic

<sup>&</sup>lt;sup>3</sup> A percutaneous endoscopic gastrostomy (PEG) is a procedure to place a feeding tube through the skin and into the stomach to provide nutrients and fluids. This also requires care to be taken to keep the skin around the entry site clean

<sup>&</sup>lt;sup>5</sup> accidental inhaling of fluid into the windpipe and lungs.

<sup>&</sup>lt;sup>6</sup> Regular appointments with cardiac service, paediatrician, and dietician, also gastroenterology physiotherapy and speech and language support, as needed/in due course

<sup>&</sup>lt;sup>7</sup> Integrated Contact And Referral Team. The "front door" to Early Help or Social Work support including safeguarding <sup>8</sup> The Multi-Agency Plan (MAP) is an early help assessment which, provides a standardised approach to identifying risks and strengths for children and families and co-ordinate access to appropriate, timely support to prevent needs escalating

3.5. The same day Sibling was made subject to a Police Protection Order and placed with foster carers. The following day the local authority obtained an Interim Care Order for both children. Sadly, within two days it was apparent that Child F would not recover, and he died after life support was ceased.

#### 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 and from parents. The themes are:
- Response to babies born with health conditions
- Communication with parents whose first language is not English and consideration of cultural background
- How practitioners and agencies worked together; making and responding to referrals
- The arrangements to safeguard and promote the wellbeing of Child F and his sibling

#### Theme: Response to a babies born with health conditions

- 4.2. Individuals with Down's syndrome present a wide spectrum of physical, cognitive, and social characteristics and abilities. However, there are some health conditions which are commonly associated with the syndrome. These were considered by clinicians and treatment was provided to Child F for his cardiac condition and feeding difficulties.
- 4.3. Parents (and practitioners) were expecting Child F to be healthy; hearing their child has health conditions and a lifelong disability to some, as yet not fully known, degree just after birth is a tremendous shock for any parent. The amount of unfamiliar information may be difficult to take in, especially if English is not your first language. Disability charities all describe the same kind of emotions typically faced by parents who have been given a diagnosis recently; shock, disbelief, denial, anger, guilt, feelings of loss for the child (and life) that the parents were expecting, fears about coping and worries about the impact on any siblings. These normal feelings can be more difficult to manage if parents have a different level of understanding or react differently to the diagnosis. In addition, feelings are likely to be influenced by individual attitudes and experience of disability and the reaction and support from the extended family. There are often extra costs and practical problems of caring for a child with health conditions, especially one in hospital. For example, neither hospital was near where parents lived and they did not have a car. Also managing responsibilities of caring for another young child (Sibling) were compounded by covid restrictions which prevented Sibling visiting either hospital with the parents, or relatives accompanying them unless present to interpret. After Child F's admission to the specialist hospital parents were not able to visit until they had had negative covid tests.
- 4.4. A leaflet about screening translated into the parents' first language had been provided to Mother during pregnancy. While providing written information is good practice, parents are not likely to take in much information at this point about a condition which they hope their child will not have. The suspected diagnosis of Down's Syndrome was immediately shared with Mother after Child F's birth and the registrar held a detailed discussion with Father a week later. There were at least two other detailed conversations between a paediatrician and parents while Child F was in hospital. It is important for information to be provided repeatedly, partly because it may be difficult to take in, but also because of the evolving nature of the treatment required for Child F's health conditions. Managers told this review that neither hospital had a specific pathway for "breaking the news" of an

<sup>&</sup>lt;sup>9</sup> Heart anomalies, feeding, speech and language development, sight and hearing impairments.

unexpected health condition or disability. As part of their "Tell it right" campaign the Down's Syndrome Society publish a very useful top tips leaflet, primarily aimed at midwives, which covers prenatal and postnatal discovery of a child having Downs Syndrome. Although specifically written for diagnoses of Downs Syndrome the tips generalise to breaking the news about all health conditions and could be a useful resource both to individual staff and agencies in developing pathways.

- 4.5. Whilst all hospital paediatric nursing staff are well used to providing day to day emotional support to parents, this, and advice about practical support, is not their primary role. Both hospitals have specialist services to provide additional support to parents and families who need it; the multidisciplinary Complex Discharge Service<sup>10</sup> (CDS) at the specialist hospital and the complex needs nurse at the local hospital. Parents would have benefitted from more effective referral arrangements to these services. A written referral to the Complex Discharge Team was made by PICU staff 10 days after admission, followed up by a phone call two days later specifically asking for transport or financial assistance because of parents' difficulties visiting. CDS staff told this review that this referral appears to have been overlooked and closed without any action due to incomplete handover between staff members associated with annual leave. 11 Despite, for example, father subsequently explaining they were struggling for money and the costs of taxis being prohibitive when contacted to ask why parents are not visiting and some concerns recorded in early September 2020 about Mother's reluctance to engage with Child F, there is no evidence that this lack of involvement from the CDS was identified by PICU staff. Practitioners told this review that the this could have been due to use of different recording systems across the hospital and a primary focus on critical care and in the expectation that Child F would be transferred back to the local hospital. Paediatric Intensive Care staff at the specialist hospital suggested there could be a role for CDS staff to visit the ward on occasion so that parents could approach them independently if they needed additional support of any kind.
- 4.6. Child F was transferred to the local hospital with a plan to establish feeds. When it became apparent a month later that there were issues with the feeding mechanisms and concern regarding safe discharge, the Complex Needs Nursing Team then became involved as the care needs had increased and the discharge was delayed and more complex than expected. However financial difficulties were not addressed in any way by local hospital until the complex needs nurse provided assistance with a Disabled Living Allowance<sup>12</sup> (DLA) application in early December 2020.
- 4.7. Helping parents to visit hospital is important for several reasons. These include: the need for contact with their baby to promote bonding; to promote their knowledge and confidence in caring for him so that he can be discharged home; to mitigate (financial) stressors which can adversely affect parenting; and to prevent either unfair criticism about lack of visiting, or difficulties for practitioners judging how concerned to be about any lack of visiting.
- 4.8. Because Child F was in hospital the community midwifery service did not have contact with him. They did have contact with Mother, however the quality of emotional support they could provide was undermined by not knowing the nature of Child F's health condition. This was because details are provided on discharge notifications, which was not applicable in this case because Child F was still

<sup>11</sup> The Complex Discharge Service Manager intends to discuss the incident with the team and review Standard Operating Procedures to reflect any learning.

<sup>&</sup>lt;sup>10</sup> The Complex Discharge Service comprises an Occupational Therapist, Nurse and part time social worker (1 day per week). The role of the team is support with care packages, home assessments, financial grant applications and coordination of long stay patients who are unable to be discharged until home and care packages are in place.

<sup>&</sup>lt;sup>12</sup> This is a benefit with a minimum level in 2021 is £23.70 per week which is intended to help with the additional costs of caring for a disabled or sick child where additional care to that required by a normal child has been required for a minimum of 3 months and is likely to persist for a further 6 months or more. https://www.gov.uk/disability-living-allowance-children

in hospital aged 28 days when midwifery services cease. Midwives can often rely on getting sufficient information from mothers, but not in this case. The midwife was aware from phone contact with the specialist hospital that the baby was "very poorly" but no details were shared because PICU does not provide information over the phone without verification of identity and a mutually agreed password, which had not been put in place. Records show Mother told the midwife she was feeling "nervous" without being sure why. The midwife does not recall this conversation. There is no evidence that this comment was considered either in the context of standard postnatal mental health screening, or the health of the baby; had the midwife known more about the nature of the baby's health conditions she might have reflected further on the comment. 14

- 4.9. Both midwives and health visiting practitioners told this review that local hospital neonatal services sometimes contact them to share progress and/or concerns. However, their perception was that occasions of contact from the PICU in the regional specialist hospital were very rare and that it would be helpful to have details of health conditions, potential dates for discharge, any concerns and details of health specialities involved in providing services. In this case the usual process for notifying health visitors of admissions and discharges to PICU was not followed on the first and third occasions for reasons which are not known, although practitioners told this review that explicit consideration of which staff on the PICU should do this might improve arrangements. Whilst midwives and health visitors appreciated the challenges of that hospital communicating safely and easily with several different services, they felt that better arrangements for communication and liaison would benefit children and their families. Practitioners suggested the development of a communication pathway, which could include development of generic email addresses for the respective hospital, midwifery and health visiting services. To be effective this would need to be a regionally agreed communication pathway. PICU staff told this review that the password system mentioned previously works well with police and Children's Social Care staff and should be reviewed for health staff. The hospitals involved in this review will consider what better information sharing with midwives and health visitors should look like.
- 4.10. During his short life Child F had two health visitors: the second became involved because of a review of caseloads. Both were energetic on allocation in their attempts to find out about Child F's health condition and progress and consider what support the family might need. The first health visitor made immediate contact with the Down's Syndrome Association, this resulted in a specialist growth chart some weeks later. In mid-January 2021 further contact by the health visitor 2 established that no written material was available in the parents' first language. Accordingly, the health visitor went through the website with interpreter's assistance on her next visit. The complex needs nurse recognised the potential value of peer support for the parents, however, an email contact for another European family with who had a child with Down's Syndrome was not provided the beginning of December 2020. This was mostly due to the inherent delays by the Down's Syndrome Association's attempts to find a willing family and gain consent to share details.
- 4.11. In the 6 months period between Child F's birth and death records indicate that parents mentioned financial difficulties (including loss of Father's job in November 2020) a minimum of five times to different practitioners; staff in both hospitals and the health visitor. The support they received regarding this involved help with completing an application for Disabled Living Allowance (DLA) during December 2020, a Christmas food and toy hamper provided by Children's Centre Services, and a referral to the Citizens Advice Bureau at the beginning of February 2021. Permission to complete the DLA claim form was not sought from Mother until the beginning of December 2020 and

<sup>&</sup>lt;sup>13</sup> The specialist hospital gets a lot of phone calls from press and the public where it would not be appropriate to provide any information, and information sharing is kept basic as not all professionals would understand the complexities of the health conditions/PICU care

<sup>&</sup>lt;sup>14</sup> There is currently an open action plan for the provision of maternal mental health training for midwives to increase their knowledge and skills when assessing and discussing mental health with mothers.

the form completed during early December 2020. This would have slightly reduced any potential entitlement as eligibility for Child F started at age 3 months; to receive full potential benefit a parent or a practitioner supporting them should either request a printed form by telephone or submit a completed form at the 3 month point, as claims for DLA cannot be backdated. Practitioners told this review that they were not aware of this.

- 4.12. Neither hospital was near the family home and no help towards travel costs¹⁵ ever seems to have been considered for a combination of reasons. For example: it was not widely known initially that the parents were dependent on taxis; the lack of involvement by the Complex Discharge Team at the specialist hospital who might have addressed this; the unusual length of Child F's stay in the local hospital; a misunderstanding that help can only be provided for people receiving benefit due to unemployment, which was not the case for Father until November 2020; and a later reliance on a referral for Early Help, including referral to the CAB. However, no offer of help from the CAB was received until February 2021. The delay appears to have been because making a referral was seen to be the responsibility of the Early Help Officer who did not become involved until mid-January 2021 and who first had to seek parent's explicit consent to make the referral. This delay was unfortunate because CAB got in touch with the family less than a fortnight from the date of the referral. The expectation in the local hospital is that parents would self-refer to the CAB; there are additional challenges with this for people whose first language is not English. Health visiting staff told this review that where people needed support to self-refer or attend the CAB they had accompanied them.
- 4.13. Practitioners told this review that whilst most practitioners would have a basic awareness of key welfare benefits, they were unlikely to understand them in detail unless they had specific experience of resolving an issue, and even then their knowledge can get quickly out of date due to benefit changes. The priority therefore is to know about the existence of the most received benefits for sick children and their families and how to access more information and advice about them. As a result of this review local hospital managers have recognised that there is a need to supply more generic information for parents who may be experiencing financial difficulty about potential sources of support and a need to encourage staff to explore potential financial difficulties associated with travel and seek advice (eg from the hospital Safeguarding Team) even if parents are managing to visit and attend hospital appointments as expected.¹6 At the specialist hospital equivalent advice could be sought from the Complex Discharge Team. Any information proactively provided to parents would need to research any alternatives to the national scheme for those who do not meet the eligibility criteria or for whom public transport is not suitable for some reason. Either the CAB or the Benefits and Welfare Service run by the council might be able to help with the production of information.
- 4.14. Covid restrictions meant that women were required to attend midwifery appointments alone. This meant that Mother did not have the option to bring a family member with her to provide support and that she was having some difficulties attending due to lack of childcare. All parents with a new baby need some level of practical and emotional support from family and friends. This is especially the case when the baby has health conditions. The parents had a relative who lived next door and at least one other family locally. The health visitor knew about the existence of the uncle that he was regarded by parents as a good source of support from previous records for Sibling; this had been where the family first stayed at the time of their arrival in the uk. Staff at the specialist hospital told the health visitor that that an uncle usually brought parents into hospital daily and that the uncle

<sup>&</sup>lt;sup>15</sup> Father told the CAB and police that the family had spent £4000 on taxi fares

<sup>&</sup>lt;sup>16</sup> This review was told that in practice local hospital staff don't make a referral to safeguarding for the involvement of the Complex Need Team unless they have concerns about visiting frequency

spoke good English. Early Help had been told by the health visitor that there were members of the extended family living close by, and that at the MAP meeting they would have discussed what specific support they were providing or could provide

#### Summary of learning: Response to babies born with health conditions

- The importance of considering the emotional impact on the parents and any siblings of an
  unexpected diagnosis of a serious health condition shortly after birth, and the need for clear
  arrangements that ensure a consistent prompt approach to "breaking the news" and the provision
  of information, advice and support from birth and in early infanthood.
- The potential impact of additional costs, eg travel when children are in hospital for prolonged periods and/or there are practical problems caring for siblings
- The importance of midwives and health visitors knowing details of babies' health conditions so they can assess mothers' mental health in the context of having a very ill baby

#### See recommendations C, E & F

Theme: Communication with parents whose first language is not English and consideration of cultural background

4.15. Prioritisation of antenatal home visits by the health visitor in response to government guidelines for Covid did not include Mothers whose first language was not English. 17 This reduced the opportunities for the health visitor to establish a rapport before birth and proactively assess needs of the whole family. Providing effective services to people whose first language is not English poses several challenges for practitioners. It is harder to contact parents spontaneously for any updates or queries, or to make appointments It is not easy to have the usual informal conversations on the ward to provide advice and emotional support. Nonetheless Mother told health visitor 2 she felt well supported emotionally by hospital staff, and she felt able to express her worries to them about managing the nasogastric tube at home. Practitioners said that this was significant because often parents do not feel able to express such worries for fear of being considered not able to cope. Where parents first language is not English it is harder to explore any unexpected behaviours or comments in a timely way, or to check understanding of information and advice given. Practitioners told this review that when Mother asked if Child F would "grow out of it" they were uncertain whether or not this was a culturally influenced misunderstanding of the diagnosis of Down's syndrome, although some elements of his health conditions were treatable or would improve over time e.g. the heart condition and feeding difficulties respectively. The need to use some form of communication aid or interpreter, at best, makes appointments longer and at worse reduces the complexity of the conversations. Barriers to easy communication make it harder to build effective partnership working relationships with parents. In addition, written information in the appropriate language is not always available and, when it is, special arrangements must be made to acquire it. Father's understanding of English is better than Mother's and practitioners established that he was literate in his first language, which made it possible to provide some information in that language, which the parents could keep and refer to again independently. This included the health visitor providing standard

<sup>&</sup>lt;sup>17</sup> As a result of this review service prioritisation criteria have been amended to include Mothers whose first language is not English

information given to all new parents<sup>18</sup> and local hospital providing a copy of the "congratulations on your new baby" from the Down's Syndrome Association.

- 4.16. Whilst English speaking family members did sometimes accompany parents or make or receive phone calls on their behalf, practitioners do not rely on family as interpreters unless there is no alternative. This is because they may not understand medical terminology and cannot always be relied upon to translate accurately or all of the intended communication by either party. Apart from an initial visit by the first health visitor without an interpreter, for reasons that are not known, all practitioners put arrangements in place to promote communication with Child F's parents. These ranged from publicly available apps like google translate and "Say Hi" for more straightforward conversations to "language line" and "communicator on wheels", which are both telephone services and the use of face-to-face interpreters for planned appointments. Hospital practitioners told this review that the questions parents asked suggested they understood what they were being told about Child F's health.
- 4.17. Interpreters are contracted by "language line" as part of a pool and tend to work part-time which makes hard to ensure continuity, and practitioners told this review that their experience of using interpreters was that some were better than others. There was also one interpreter that Mother expressed reservations about. Sibling's social worker managed to arrange with "language line" to use the same interpreter for several contacts with Sibling and told this review that the best approach was to arrange this from the very beginning, which also tended to promote more commitment and flexibility from the interpreter. This was more likely to be productive that the unsuccessful request for the same person again after a positive session, which another practitioner described after specifically involving a female interpreter to visit Mother.
- 4.18. Practitioners told this review that although some written guidance was available for the "communicator on wheels," specific training for working with interpreters was not generally available. Training would emphasise the importance of the practitioner setting up any session by describing the scope of the intended conversation, clarifying any relevant context and likely challenges from both parties' point of view, and checking that there would be no barriers due to attitudes of the interpreter or links in the community, which can be an issue for some individuals, even though they speak a common language. A set up conversation would also usefully include a proactive discussion about any relevant cultural considerations.
- 4.19. Cultural issues and difficulties in communication seem to have caused some delays in Child F's discharge from hospital. Hospital staff were worried about parents' management of the nasogastric tube and ability to summon help if they had difficulties. Mother was more hesitant than Father about Child F having the PEG procedure which was necessary for him to be discharged safely home. This may have been due in part to being used to a different health system in their home country where such procedures would have to be paid for. Practitioners also had no way of knowing the parents' experience of receiving health services prior to their arrival in the UK, nor how well the family had engaged, which they would have done had the family always lived in the UK.
- 4.20. In this case, until the incident that prompted this review, there is no evidence of proactive effort by practitioners to find out more about the family's cultural background and the potential impact on Child F's care. Practitioners told this review that this may have partly been due to the immediate need to focus on treating and managing Child F's health conditions. For example, Health Visitor 2 told this

<sup>&</sup>lt;sup>18</sup> The health visitor provided health resources in the parents first language; Safe Sleep' from the Lullaby Trust and 'ICON' leaflet (*Infants cry, Comfort, Its OK*, *Never shake a baby-* information for parents to support safe handling of the infant and prevent abusive head trauma).

review that on reflection, her initial priorities were Child F's health needs, obtaining information in the parents' first language and making a referral to Children's Services for more support. This meant she hadn't prioritised finding out more about the family's culture, not least because understandably she had anticipated an ongoing relationship with them. There is evidence of one occasion where an interpreter volunteered relevant information regarding the potential impact of the parents' cultural background, and ICART knew that attempts were being made to connect the family with another family from the same background who had a child with Down's syndrome.

- 4.21. Practice in this case echoes findings from a recent national report<sup>19</sup> into non accidental deaths of babies under 12 months old which found limited evidence that the impact of ethnicity and culture on parenting was being considered. The report concluded that practitioners need more confidence to acknowledge and explore this. For cultural reasons, it was even more important than it usually would be that discussions about Child F's health were held with both parents; one of the interpreters told staff at the local hospital that in the parent's country mothers would predominantly care for children so Father would need more involvement in discussions. Staff at local hospital also had experience of working with another family from the same cultural background. That mother had explained that the diagnosis of Down's Syndrome was not recognised in their country and she had not told the father about it until the baby went home from hospital.
- 4.22. Practitioners told this review that they would welcome some training about the cultural backgrounds of the small populations of BAME people that had recently begun to arrive in Halton. This would usefully include how to find out about less common cultural backgrounds with which they were (still) unfamiliar. As well as using interpreters to find out more about a family's background, practitioners suggested seeking advice from adjoining areas with higher numbers of the relevant populations; sometimes this had resulted in key agencies having specialist staff who could be a resource, or there might be a relevant community or faith organisation. However a wider consideration of the relevant community in other parts of the UK could also be helpful, and would have been for this case.

## <u>Summary of learning:</u> Communication with parents whose first language is not English and consideration of cultural background

- The benefits of having the same interpreter for parents who need long term support and the need to request this in advance, at first contact with any interpreting agency
- The value of specific training for practitioners about establishing effective working relationships with interpreters
- The benefits of "set up" conversations between practitioners and interpreters
- The importance of considering parents' cultural backgrounds; whether and how they might affect their understanding and response to their child's diagnosis and their expectations of treatment
- The benefits of providing written information in parents' first language; standard information for new parents and specialist information about any health conditions

#### See recommendation A

Theme: How agencies worked together: making and responding to referrals

<sup>&</sup>lt;sup>19</sup> Walters A et al (2021) Fieldwork report: National Review of Non-Accidental Injury in under 1s Child Safeguarding Practice Review Panel

- 4.23. At the end of October 2020, the local hospital consultant requested nursing staff make a referral to the Disabled Children (social work) Team for additional support. No referral was made to Children's Services for 3 weeks. Delays were caused firstly by misunderstanding about the correct service as the named nurse for safeguarding at the local hospital advised that Child F's circumstances would not meet the criteria for the Disabled Children's Team. Although the named nurse was in fact referring to the local authority in which the hospital was located rather than the one in which the family lived, Child F would not meet the criteria there either as the service is for children who require "short breaks" respite care, which is not normally considered appropriate for very young children. A further delay was caused by deciding whether the nursing staff or the health visitor would gain consent and make the referral.
- 4.24. As carers for a disabled child the parents would have been entitled to an assessment of their own needs for support.<sup>20</sup> These are completed by a Carer Assessment and Support Worker from the council. None of the practitioners involved had come across these before. It was not clear what relationship they might have with any Multi-Agency Plan (MAP), or Child and Family Assessments conducted by a social worker, including those Child and Family Assessments which should be completed for children who have been in hospital continuously for 3 months. Child F should have been identified as needing such an assessment (with parental consent) around the time the health visitor made the referral to ICART. Hospitals have a duty under the Children Act 1989 to notify the local authority so that an assessment can check that the child's welfare is "adequately safeguarded and promoted". Practitioners who were working with the family were not aware of this. The specialist hospital has arrangements to identify and refer children who have been inpatients for 3 months or more. Managers from the local hospital told this review that the context for this being over looked for Child F was that it is unusual to have a child so long in hospital and recognising the total length of continuous hospital stay was complicated by the previous stay in the PICU elsewhere. Arrangements have been put in place in the local hospital and ICART staff to recognise the 3 month point when applicable for any future inpatient child.
- 4.25. The health visitor's referral to ICART was considered by social care and early help managers and passed to the Early Help Support Nurse for detailed consideration. By the beginning of December 2020, the support nurse had gathered further information from relevant agencies and produced recommendations to be undertaken by staff at the local hospital, an Early Help Officer and the health visitor respectively, with some suggested referrals to be made by either the health visitor or the Early Help Officer, to be agreed by them. The list was shared with those practitioners/services and was comprehensive and, in the authors opinion, appropriately in a priority/and or chronological order. However, no explicit priority or timescale was linked to any of the actions, and the referral to the CAB was one of the ones that was for discussion by health visitor and Early Help Officer.
- 4.26. No Early Help Officer was allocated until mid-January 2021. This appears to have been because when a manager contacted the health visitor to get an update within the expected 2-week timescale for first contact with the family or practitioners working with them, Child F was shortly due to have the PEG fitted and soon to be discharged home. Early Help staff told this review they would have become involved while Child F was in hospital had they had the referral earlier. Whilst the difficulties of attending the discharge meeting subsequently arranged at short notice are acknowledged, the fact that there would be one was foreseeable. It would have helpful for an Early Help Officer (EHO) to have been allocated to attend it to meet the parents and participate in the discussion about support after discharge. It was a positive step by the health visitor to invite the EHO to the meeting:

<sup>&</sup>lt;sup>20</sup> Under the Children Act 2014 A Parents carer needs Assessment should be provided if it appears to LA that parent needs support or if parent requests one. The assessment should consider 'the well-being of the parent carer' and 'the need to safeguard and promote the welfare of the disabled child - -and any other child for whom the parent carer has parental responsibility.'

practitioners told this review that EHOs allocated to children subject to Children in Need or Child Protection plans were routinely invited to discharge meetings at local hospital but not usually otherwise. By the time Child F was discharged it was almost Christmas and the impact of encouragement for council staff to take mandatory unpaid annual leave over the Christmas period means that non-emergency services are not in work for almost 2 weeks, hence delaying allocation until a time which was nearly 2 months after the referral had been made to ICART.

- 4.27. As the health visitor had not yet been part of the training programme being rolled out to complete MAP assessments, support to complete a MAP was to be provided by the Early Help Officer. However even had the health visitor done the training she might still have requested extra support to get the MAP done in the timeliest way given the complexities of Child F's needs. Once involved the Early Help Officer was energetic in her attempts to contact parents and relevant agencies/practitioners. The MAP was sent to the parents by early February 2021. Covid restrictions had an impact on the arrangements, preventing the usual home visit and convening of a multi-agency meeting involving the parents to develop the MAP, which would have given the parents more opportunity to indicate what they thought the priorities for support were. In addition, covid restrictions prevented a welcome visit to the sensory room or "soft play" room at the local Children's Centre and groups for parents run by the Down's Syndrome Association had been suspended due to the covid pandemic.<sup>21</sup>
- 4.28. According to records, initially the plan of the Early Help Officer was to cease the MAP once all agreed referrals had been made; after reflection this was changed to holding a review meeting in 6 weeks. This did not happen due to the incident which prompted this review.

#### Summary of learning: how agencies worked together, making and responding to referrals

- Where Early Help Officers will be involved in providing support after discharge from hospital there
  are potential benefits to families of their being invited to and attending discharge meetings. This
  should be considered even when the involvement is for "early help" rather than Child in Need or
  Child Protection plan.
- That a child who has been in one or more hospital settings for 3 continuous months or more is entitled to be offered an assessment of their welfare needs by a social worker.
- Parents who are caring for a disabled child are entitled to a carer needs assessment conducted by an officer from the council Disabled Children's Service

#### See recommendation D

Theme: The arrangements to safeguard and promote the wellbeing of Child F and his sibling,

4.29. Child F was a new-born baby who was entirely dependent on the care provided by the adults responsible for them. Children under 12 months consistently form the significant minority (approximately 40%) of children subject to Serious Case Reviews/Child Safeguarding Practice Reviews.<sup>22</sup> Child F was pre-verbal and could not tell professionals about his lived experience, although there is evidence in a number of agency records of observations of his presentation and the way that his parents responded to him.

<sup>&</sup>lt;sup>21</sup> Since the period covered by the review these have re-opened

<sup>&</sup>lt;sup>22</sup> Sidebotham P et al (2016) <u>Pathways to protection a triennial analysis of Serious Case Review 2011-14</u> Department for Education and all previous analyses of SCR/CSPRs published by the government of the day

- 4.30. Research shows that disabled children are more vulnerable to abuse than non-disabled children<sup>23</sup> The reasons for this include: attitudes and assumptions by practitioners that either believe it does not happen or accept forms of behaviour management that would be seen as abusive for any other child; a reluctance to challenge carers who are already under significant pressure; dependency by the child on others to meet personal care needs; communication barriers; misinterpretation of behaviours (eg self-mutilation, masturbation) that in other children might raise safeguarding concerns; isolation from other children and adults, including the family if the child is in residential care. Although the research relating to children from BAME backgrounds is limited, there is evidence of double discrimination for them if services (including when investigating allegations of abuse) are not sensitive to their cultural and language needs.
- 4.31. During the police investigation after Child F died it came to light that Father had convictions for domestic abuse against a previous partner in another country. This was not known previously to any practitioner working with the family, had this been known there would have been a heightened awareness about the potential for violent behaviour by Father and possible risks to the children. However there have been no concerns about domestic abuse between Father and Mother known to practitioners and no concerns about Father's behaviour towards either Child before the injuries which prompted this review
- 4.32. Studies of Serious Case Reviews have shown that for disabled children, signs of abuse and neglect may be masked by, or misinterpreted as due to health conditions or underlying impairments.<sup>24</sup> The term "Diagnostic Overshadowing", 25 which was first used to describe the misdiagnosis of other conditions for adults with learning disabilities may have some relevance in this case in terms of the initial response that Child F received after "collapsing" at home. For example, relatives told ambulance personnel about his heart condition. The non-medical call handler subsequently reported a cardiac arrest to the police in line with the ambulance service guidance. The police closed that first report down in error, without initiating further enquiries with medical professionals at the hospital or liaison with Children's Social Care to establish the full circumstances as they should have done. The reasons the call was closed are not known, but a relevant context maybe that records show that the ambulance call handler had said "nothing like that" in response to a question about whether there was anything suspicious. This review was told that nursing staff at the local hospital did not initially suspect non accidental injury, although the paediatrician did appropriately initiate the Acute Life-Threatening Event (ALTE)<sup>26</sup> arrangements under the then applicable the Sudden Unexpected Death of an Infant or Child (SUDIC) procedure (2019), which involves contacting the police and Children's Social Care, as there was no clear medical cause of Child F's condition. This is in place because, for a proportion of ALTE children, further tests do show evidence of non-accidental injuries, which proved to be the case when Child F was transferred to the specialist hospital for treatment.
- 4.33. After being notified of the ALTE the police attended the local hospital promptly. The police were told by nursing staff that they could not have access to Child F's clothing and equipment, without a written request from a Chief Inspector or above. This kind of delay can have a detrimental effect on any subsequent criminal investigation; the legal position has since been clarified within the hospital trust that the items could have been released as part of a criminal investigation, this information will be shared with staff as an action from this review. Hospital managers told this review that staff appear

<sup>23</sup> Safeguarding Disabled Children; practice guidance (2009) Department for Children Schools and Families

subsequent intensive care/high dependency unit admission and remains unexplained".

<sup>&</sup>lt;sup>24</sup> Sidebottam P et al (2016) <u>Pathways to harm pathways to protection</u>; a triennial analysis of Serious Case Reviews <u>2011-14</u> Department for Education

<sup>&</sup>lt;sup>25</sup>Definition of Diagnostic Overshadowing "once a diagnosis is made of a major condition there is a tendency to attribute all other problems to that diagnosis, thereby leaving other co-existing conditions undiagnosed,"Neurotrauma Law Nexus <a href="http://www.neurolaw.com/neuroglossary/">http://www.neurolaw.com/neuroglossary/</a> cited by Blair J (2018) Diagnostic overshadowing; see beyond the diagnosis in Intellectual Disability & Health – March 2018 <a href="http://www.intellectualdisability.info">http://www.intellectualdisability.info</a> University of Hertfordshire <sup>26</sup> the definition of ALTE is "a sudden collapse of an infant requiring some sort of active intervention/resuscitation and

- to have confused the process with that for obtaining medical records, which does require written authorisation.
- 4.34. After Child F's death there was a delay in convening the multi-agency Rapid Review meeting which is required under the Sudden Unexpected Death of an Infant or Child (SUDIC) procedures. This was due to confusion about who would convene this meeting. Multi-agency arrangements in the area where the specialist hospital is located are different to those for where Child F lives, as the respective areas are covered by different safeguarding partnerships (and two different police forces). Halton partnership business staff have taken over the responsibility to convene future SUDIC meetings for children in their area who die at the PICU pending a review of this aspect of the pan-Cheshire arrangements.
- 4.35. In their contact with ICART, the police and both hospitals mentioned the existence of Sibling. Police made contact with ICART via email to request information on the family such as family composition and details for parents and Sibling. The email from the police reports it was an ALTE incident, but which could well progress to a SUDIC. Practitioners told this review that despite a contact being loaded on the electronic record for each child pending further information from Police and ICART, it would have been preferable if ICART had been more proactive, for example by seeking more information by telephone from the hospital and liaised with the police. Although there were no safeguarding concerns known initially, the Emergency Duty Team (EDT) and the police would subsequently have been better placed to respond to both children's needs once they received confirmation that Child F had non accidental injuries, in the early evening, via the specialist hospital safeguarding consultant. Risks to Sibling were considered by EDT social care staff, the time of day meant that her eventual placement with Emergency foster carers was not until the early hours of the morning. This is not ideal for any child but can happen if it is not known for sure until the evening that a placement will be needed.<sup>27</sup>
- 4.36. Local hospital practitioners told this review of their perception that partner agencies are sometimes confused about the expected response to ALTE when there are no immediate safeguarding concerns. This view was shared by the police. Since the death that prompted this review the local Sudden Unexpected Death of an Infant SUDIC procedures have been reviewed and the new ones<sup>28</sup> make more explicit mention of ALTE both in the title and the content. However, the document is almost entirely focused on SUDIC, it is very lengthy and not easy to navigate. It is difficult to locate references to ALTE, which do not recognise that despite many ALTEs are the result of NAI, but that this is often not apparent immediately, as in this case.<sup>29</sup> The required initial response from ICART, where there are no immediately obvious safeguarding concerns (to check records for current and previous involvement and provide information to hospital staff and the police about the family background), remains the same. Practitioners suggested that there would be benefits in considering separating out the ALTE element from the SUDIC guidance to make them more visible; perhaps developing a standalone flowchart and separate forms rather than having to adapt the ones referring to a child's death as practitioners currently must. In addition, they suggested for example, that it would be beneficial to convene strategy meetings under the safeguarding procedures as these can be subsequently ceased if they turn out not to be necessary. This suggestion is much more practical than it would have been prior to the development of virtual meetings due to covid.
- 4.37. The Children Act 1989 requires that the first consideration in placing children away from their parents should be whether they can be placed with other family members. Emergency Duty Team (EDT)

<sup>&</sup>lt;sup>27</sup> Speculative requests for foster carers are hard to manage as many of them are subsequently not required.

<sup>&</sup>lt;sup>28</sup> (Pan Cheshire) April 2021 Sudden Unexpected Death of an Infant (SUDIC)or Child and Acute Life-Threatening Event (ALTE) that are unexplained and/or suspicious requiring resuscitation and intensive care interventions in children

<sup>&</sup>lt;sup>29</sup> Ibid page 59 reference to the guidance being used for "cases of ALTE (Acute Life-Threatening event) where the child may have survived but is highly likely to suffer / has suffered significant harm.

staff felt this was not safe or practical at the time of day a placement was needed. The usual local practice is that children placed with Emergency Carers are moved on within 6 days. Sibling stayed with Emergency Carers for 4 weeks, an exception had been made to ensure a placement was found where Sibling could then stay as long as might be needed. Several family members had put themselves forward to be considered as temporary foster carers pending more detailed assessment. Unfortunately, this was not feasible due to the early stage of police enquiries which meant it was not possible to be clear who had had care of Child F during the time when the injuries had been caused. Arrangements were subsequently made for full kinship fostering assessments of those relatives to be undertaken by a social worker who spoke the same first language.

4.38. The local authority was not able to secure a placement with foster carers whose first language and culture was the same as that of Sibling. This would be difficult in most local authorities unless there was a large settled relevant community nearby, which there isn't in this case. The local authority was able to find a carer from the same background who did not have a vacancy, but who was able to provide advice to the Emergency Carers. Records show that the subsequent foster carers have worked well with members of Sibling's family members, who have provided food and information about special days in their country of origin. One of the carers has begun to learn Siblings first language.

# <u>Summary of learning:</u> The arrangements to safeguard and promote the wellbeing of Child F and his sibling

- Recognition that for disabled children signs of abuse can be masked or misinterpreted due to assumptions about ongoing health conditions or impairments
- The challenges of agencies working across different geographic or organisational boundaries when different procedures apply in different areas
- The importance of recognising the potential for Acute Life-Threatening Events (ALTEs) to later turn out to be due to abuse

#### See recommendation B

#### 5. PARENTS' VIEWS

- 5.1. The author obtained feedback about services received from each parent separately using video technology. Overall, both parents felt generally felt positive about the care and support they and Child F received after his birth, while he was in hospital and after he came home. Mother said it was important that practitioners provided emotional support for the parents, as well as good care for sick babies and Father said the treatment had improved Child F's health. Both parents appreciated that practitioners routinely involved interpreters. Mother felt the practitioners she met were helpful and gave her information about how to care for Child F and gave her benefits advice, access to free milk and syringes. Father mentioned appreciating meals being provided for them at hospital and help to apply for the Disabled Living Allowance benefit for Child F.
- 5.2. Mother said she understood what she was being told about Child F. She felt that she got more information about Child F's health conditions than she might have received in her country of origin. Specific information she particularly remembered is being given the leaflet (in her first language) about crying and not shaking babies and support to get information from the internet about Child F's health conditions. Father did not feel the range of health conditions that affected Child F were fully explained to him and seemed to think that these were additional to rather than being associated with the Down's Syndrome. He felt information was given to his wife primarily rather than him.

5.3. Mother mentioned two things as being particularly difficult. One was not having much money so it was difficult to go and see Child F in hospital, especially when he was in the specialist hospital due to the distance. The other was Sibling having to live with Foster Carers, but that her sisters had been able to reassure to reassure her that Sibling was being well looked after. Father asked for information about how Sibling was doing and for a photo of her; these requests were passed onto the social worker.

#### 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. This case includes the following examples that have not been previously mentioned in this report.

#### Protective and supportive actions by practitioners

Because of Child F's complex health needs and knowing she would be significantly involved with the family once he was discharged home, the health visitor conducted the primary visit in hospital. instead of waiting until the baby had been discharged, which was more common practice.

Trial run of parent administered medication and accessing support arrangements with Hospital at Home nurse as part of discharge planning

Detailed schedule of support and visits drawn up and delivered for the early days after Child F's discharge home. This included weekly visits by health visitor after taking over care from hospital at home team; growth monitoring, on-going assessment of health needs, view of living and sleeping areas and observation of positive interactions with Mother and Father. Child F had also been placed on "open door" with local hospital paediatric service which meant he could be brought at any time without an appointment

The Police family liaison officer collected Siblings personal belongings to help Sibling feel more at home with the foster carers. information from health visitor records about Sibling liking drawing was shared with the foster carers

Practitioners in contact with Sibling after her admission to care recognised that apparent signs of developmental delay might be temporary due to the trauma of being removed from her family

The complex needs nurse recognised that the parents would need help to complete the remainder of the DLA form over and above her completing the section for professionals and arranged for an interpreter to support her to assist them with this

The Early Help Officer identified and attended training on working with children and families whose first language is not English

The parents were enabled to be with Child F when he died.

The CAFCASS guardian appointed for the care proceedings could speak directly to Sibling as she spoke the same language

The health visitor made a visit to Sibling within a few days of the placement with foster carers, a 2nd follow up visit a week later

The Family Placement service identified someone who spoke the same language to complete the assessments family members as potential kinship foster carers

#### 7. CONCLUSIONS AND LESSONS LEARNED

One of the national triennial studies of Serious Case Reviews concluded that "For many of the children, the harms they suffered occurred in spite of all the work that professionals were doing to

support and protect them".<sup>30</sup> This applies to this case where there were many examples of positive practice, including support which Mother and Father specifically mentioned they appreciated, and there were no indications that Child F was likely to come to significant harm until the discovery of the injuries that prompted this review. Nonetheless there were examples of where services could have been more proactive in ensuring the family received some elements of support earlier. Consequently, there are some areas of learning which will enable local agencies to improve services for other children who are born with serious health conditions, especially if their families have recently arrived in the UK with English not being their first language.

#### 8. RECOMMENDATIONS

The individual agency reports have made single agency recommendations. Halton Children and Young People Safeguarding Partnership Safeguarding Children Partnership (HCYPSP) has accepted these and will ensure their implementation is monitored. To address the multi-agency learning, this Child Safeguarding Practice Review identified the following recommendations for HCYPSP.

- A) That HCYPSP seeks assurance from partner agencies that they have or will develop training and briefing materials for practitioners about working with BAME people. This should include;
- a. Input on the cultural background of BAME groups now living in Halton. Training should include how to find out about unfamiliar families' cultural backgrounds
- b. meeting needs of people whose first language isn't English including working with interpreters
- B) That HCYPSP share the learning form this review with the Child Death Overview Panel (CDOP) and request they ensure this is considered in the current work being undertaken on revision and implementation of the SUDIC procedures. This should include the development and dissemination of a specific ALTE pathway flowchart. The ALTE element might be usefully informed by data collection regarding the percentage of ALTE that are subsequently identified as NAI. The effectiveness of the new guidance might be measured by a baseline audit now regarding awareness of ALTE repeated 12 months after the new procedure has been implemented
- C) That HCYPSP seeks assurance from all hospitals caring for local children that arrangements are in place to improve practitioner awareness about practical and financial help for parents with children in hospital, this could include requesting an organisation with relevant specialist knowledge to produce briefing materials
- D) That HCYPSP seeks assurance all hospitals caring for local children and Children's Services that arrangements are in place to improve practitioner awareness about assessment entitlement for children if they stay in one or more hospital settings for 3 or more consecutive months and for parents caring for disabled children. This will require clarity from Children's Services about how to manage situations where both assessments might be required.
- E) That HCYPSP Seek assurance from relevant hospital and community trust health partners that they are considering how best to improve information sharing between Neonatal and Paediatric Intensive Care services and midwifery and health visiting services.

<sup>&</sup>lt;sup>30</sup> Sidebottam P et al (2016) <u>Pathways to harm pathways to protection; a triennial analysis of Serious Case Reviews</u> 2011-14 Department for Education

- F) That HCYPSP seek assurance from all hospitals that provide neonatal care for babies living locally that they have effective pathways to enable staff to break the news and provide prompt support for families whose babies are diagnosed with an unexpected health condition or disability.
- G) That HCYPSP seeks assurance from each agency involved in this review that learning points have been identified and action has been/or is being taken to address and disseminate them.