

01. BACKGROUND

At birth Child F had a cardiac abnormality. Down's Syndrome was also suspected; this was only identified at birth as tests during pregnancy had shown a low risk. Child F spent 3 months in hospital before being discharged home.

Child F died age 6 months as a result of head, spinal and eye injuries. It was also found that he had healing fractures and a previous brain injury. His father was convicted of murder. Mother was convicted for allowing his death. The family are of European heritage, English is not their first language; they arrived in the UK in 2019. Child F had one older sibling.

02. WHAT DID WE LOOK AT?

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

03. THE MAIN THINGS WE FOUND:

Supporting families; sick & children with a disability

- An unexpected diagnosis of a serious health condition shortly after birth can have a significant emotional and practical impact on parents and siblings
- Where children remain in hospital for prolonged periods, parents can face significant challenges due to additional costs, eg travel, and practical problems caring for siblings.
- Practitioners took extra steps to support the family and address vulnerabilities, the health visitor visited them in hospital, the nursing staff offered a pre-discharge trial run of medication and accessing help from home and a robust visiting schedule was drawn up for early days after discharge

07. WHAT CAN YOU DO NOW?

Think about the learning from this review and the children and families you work with. In particular:

- Remember that, as well as emotional support, advice and information, prompt practical and financial support is important to families with a sick child in hospital
- When you are not familiar with a family's cultural background take steps to find out so you can consider the potential impact on their parenting e.g, ask them, and seek advice from a relevant specialist worker or voluntary organisation or from practitioners in areas with significant similar populations
- Remember that some Acute Life-Threatening Events turn out to have been caused by abuse and that abuse of disabled children may be masked by, or misinterpreted as due to health conditions or underlying impairments
- Consider your arrangements in relation to including fathers & other adult care givers when providing information /services to unborn children and families.



06. WHAT WILL WE DO NOW?

- A) Develop and disseminate a specific Acute Life-Threatening Event (ALTE) pathway flowchart
Check that:
- B) Partners have effective arrangements for practitioners to find out about unfamiliar BAME cultures and working with interpreters
- C) Local hospitals have arrangements to improve practitioner awareness about practical and financial help for parents with children in hospital.
- D) Local hospitals and the Children's Trust have arrangements 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 children with a disability.
- E) Local hospital and community health trusts have improved information sharing between Neonatal and Paediatric Intensive Care services and midwifery and health visiting services.
- F) Local hospitals that provide neonatal care 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.

05. THE MAIN THINGS WE FOUND

Protecting sick & children with a disability

- When a child has a disability, 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.

04. THE MAIN THINGS WE FOUND

Supporting families; culture and language

- It is important to consider parents' cultural backgrounds; whether and how they might affect their understanding and response to their child's diagnosis, their expectations of treatment and their parenting
- Parents appreciated the efforts that practitioners made to involve interpreters and get written information translated into their first language
- Practitioners would welcome training about establishing effective working relationships with interpreters.