



# **Serious Case Review**

## **Child A**

**January 2021**

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# 1 Executive Summary

1.1 As part of an internal review of a paediatric gastroenterology department, Child A was identified as one of several children about whom concerns had been raised in respect of Fabricated or Induced Illness (FII). The hospital (1)<sup>1</sup> Gastroenterology team commissioned its review to understand team functioning and governance issues contributing to children having received inappropriate diagnoses, uncritical long-term treatment and a sub-optimal level of care.

1.2 This complex case was subsequently escalated to the City & Hackney Safeguarding Children Board and a Serious Case Review (SCR) initiated. The SCR report sets out a range of findings and key messages about what practitioners and agencies need to do differently. A number of recommendations for improvement are also made. In summary, the SCR found the following:

- **Practitioners did not consistently listen to the voice of Child A so as to understand Child A's perspective, concerns and feelings in order to undertake a meaningful assessment.** This was a feature across agencies. Child A's voice was strikingly absent from records.
- **Some of Child A's reported symptoms were responded to without any objective assessment by health professionals.** This led to unnecessary and inappropriate medical intervention. FII was investigated as part of a child protection enquiry when Child A was ten years old, but unsubstantiated. The SCR sets out a basis for reframing existing guidance concerning the management of suspected FII and "*perplexing presentations*".
- **There was an absence of a lead professional to co-ordinate and communicate the input of different agencies.** This risked diagnosis and treatment being based on inadequate information and inappropriately left Child

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<sup>1</sup> **Hospital 1 = Provides Secondary and Tertiary Care.** Secondary care describes services a child can be referred to if they need to be seen by someone with more specialist knowledge. A referral from a primary care practitioner is required to access secondary care. Tertiary care describes the specialist end of the NHS that provide services for very complex or rare conditions. A referral from a secondary practitioner is generally required to access tertiary care. Child A received Tertiary services at Hospital 1

A's parents with the responsibility to pass communications and information between practitioners.

- **The absence of a local chronic pain team contributed to the inadequate monitoring and supervision of Child A's long-term medication.** Following a period of hospitalisation, Child A was discharged on the analgesic Fentanyl. Over a period of six years, no professional was overseeing Child A's pain management or the impact of long-term opioid use.
- **There were weaknesses in practice to monitor the repeated postponement or cancellation of Child A's health appointments by the parents.** Despite practitioners identifying concerns in this respect, there is little evidence that these were raised in supervision, effectively responded to or that local policy was followed.
- **There was an insufficient response in meeting Child A's educational needs.** Child A became 'lost' in the system and there were no reviews held on Child A's educational progress for four years.
- **Practitioners insufficiently challenged and escalated their concerns about Child A.** The review identified many examples when practitioners should have escalated their concerns and been more critically challenging of decisions made by others that impacted on Child A's safety and wellbeing. It was not until Child A was ten years old that a referral was made to Children's Social Care.

## 2 Introduction

2.1 The Serious Case Review (SCR) involving Child A was initiated by the City & Hackney Safeguarding Children Board (CHSCB)<sup>2</sup> in December 2017. Concerns escalated to the CHSCB at the time related to:

- The amount of Fentanyl (an opioid) prescribed to Child A for pain management since the age of five. Fentanyl was initially prescribed to cover a brief surgical procedure at hospital (1)<sup>3</sup>. It was still being prescribed to Child A following discharge home.
- Suspected Fabricated or Induced Illnesses (FII), which had been investigated as part of a section 47 enquiry and concluded by Children’s Social Care as being unsubstantiated.
- The known details of the case highlighting concerns about inter-agency working and the care provided to Child A.

2.2 Child A had also been identified as part of a cohort of children in a review of the gastroenterology services at hospital (1)

2.3 The SCR covers the period from Child A’s birth to the age of 11, although the ante-natal period leading up to Child A’s birth was also considered.

2.4 To reinforce both the context and the importance of the identified themes and to hold Child A at the centre, the SCR has adopted a *child’s rights approach*. Findings and recommendations are presented with reference to relevant articles of the United Nations Convention on the Rights of the Child (UNCRC).<sup>4</sup>

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<sup>2</sup> The CHSCB was abolished in September 2019 and replaced by the City & Hackney Safeguarding Children Partnership (CHSCP).

<sup>3</sup> Hospital 2 -. Tertiary care describes the specialist end of the NHS that provide services for very complex or rare conditions. A referral from a secondary practitioner is generally required to access tertiary care.

<sup>4</sup>[https://downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC\\_united\\_nations\\_convention\\_on\\_the\\_rights\\_of\\_the\\_child.pdf](https://downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_united_nations_convention_on_the_rights_of_the_child.pdf)

### 3 Overview

- 3.1 Child A was born by emergency caesarean section at 27 weeks gestation and transferred to the neonatal unit for intubation and ventilation. During this time, Child A was diagnosed with *Necrotising Enterocolitis*, a condition of premature babies where a portion of the bowel becomes inflamed. The health visitor initially saw Child A whilst in hospital (3)<sup>5</sup>. Child A was discharged home aged eight weeks and the health visiting team undertook a new birth review. Child A was reported to be breast feeding on demand and passing both stools and urine satisfactorily.

#### ***Appraisal of Professional Practice***

*The health visitor undertook a visit to meet Child A and the parents on the neonatal unit. This is an example of good practice where developing an early professional relationship with a family can help support effective service delivery in the future.*

- 3.2 During the first year of Child A's life, there were increasing concerns raised by both mother and professionals about feeding, weight gain, constipation, excessive crying and developmental progress. Child A was being monitored by the neonatal team at home and by the neurodevelopmental clinic. The neurodevelopmental clinic referred Child A to a paediatric gastroenterologist, a dietician and an occupational therapist.
- 3.3 Child A underwent a series of tests and was prescribed medication and nutritional supplements. Mother declined health visiting support, although the neonatal team continued twice monthly home visits to weigh Child A. In late 2007, Child A's mother reported to the neonatal team and dietician that Child A had measles.

#### ***Appraisal of Professional Practice***

*The neonatal service visited twice monthly for the first three years to weigh Child A. It is unclear why. Prior to the publication of the Neonatal Toolkit in 2009 there was no local service specification to guide practice. The neonatal service reported*

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<sup>5</sup> Hospital 3 = Secondary Care Hospital

*to the independent reviewer that there was no-one else available to weigh Child A.*

*Given that Child A's weight gain was so poor, the neonatal service should have escalated this issue. There was a lack of oversight of professional roles and boundaries, no evidence of supervision and no effective engagement with the wider multi-disciplinary team or health visiting service. This pattern of working by the neonatal service meant that Child A did not receive a health visiting service and the full Healthy Child Programme. This would have provided Child A with health development and health promotion support. Another possible consequence of the neonatal service visiting so often and for so long is that mother might have felt overwhelmed by the number of involved professionals, influencing her decisions not to see the health visitor and subsequently refusing support through the local children's centre.*

*Child A underwent a wide range of medical and surgical investigations in the first year of life. Many of these were invasive and illustrate the beginnings of the over-medicalisation of Child A. Child A was reported to be suffering from ever increasing conditions, leading to more and more health professionals being involved. It would appear that when one problem was resolved (often with intrusive medical intervention) another issue would occur. These interventions appear to have taken place potentially due to over reliance on mother's reporting. The review found no evidence that professionals had directly observed Child A to witness symptoms. Given Child A was reported not to be feeding well and was not gaining weight (despite nutritional supplements), a period of observation in hospital (3) would have provided assurance that there were organic reasons for the symptoms. With limited communication between any of the services, Child A seems to have been lost in a medical intervention model.*

3.4 In Child A's second year of life, Child A's weight remained below the 0.4<sup>th</sup> Centile, and tube feeding via the nose<sup>6</sup> was commenced. A PEG<sup>7</sup> was later inserted. Child

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<sup>6</sup> Nasogastric tube feeding

<sup>7</sup> A Percutaneous Endoscopic Gastrostomy (PEG) is a procedure involving a flexible feeding tube being placed through the abdominal wall and into the stomach. This allows nutrition, fluids and/or medications to be put directly into the stomach.

A was supported by the community children's nursing team (CCNT) and was referred to the community neurodevelopmental team and speech and language therapy (SaLT). Following SaLT assessment there is limited evidence of Child A being taken for SaLT appointments and Child A was ultimately discharged from the service in 2010.

- 3.5 Mother continued to decline health visiting support, although the health visitor continued to liaise with other professionals to ensure communication was maintained and access to health visiting remained open. The health visitor had supervision regarding the family declining support and undertook a safeguarding risk assessment. This focused on Child A's non-compliant immunisation status.

***Appraisal of Professional Practice***

*Despite extensive nutritional supplements, Child A was not gaining weight, although a hypothesis is that because Child A had been born prematurely with gastroenterology problems, there was an established expectation from professionals that Child A would be slow to gain weight.*

*The review identified very limited records as to what SaLT services were provided. Where they did exist, they were often scant and process led. There was no evidence of any robust action to either plan or review Child A's care in this context. This allowed for the case to drift. Child A appears to have been discharged from the SaLT service without challenge or consideration that Child A's needs were likely to impact on future speech and language development. The SaLT Safeguarding Children Policy at the time was clear about what to do when a child missed an appointment. However, the policy was framed to take action for children about whom there were identified safeguarding concerns. SaLT staff did not see Child A in this context and hence no action was taken.*

*Discharging children who are not brought to appointments has been identified as a safeguarding risk in many SCRs. Children who are not brought to an appointment have an identified need that is then not addressed. Discharging*



*such children without a requirement to reassess the need is potentially neglectful and can contribute to ongoing harm.*

*The health visitor appropriately accessed clinical supervision, although it is not clear what her safeguarding concerns were and whether therefore there was an escalation to safeguarding supervision. The safeguarding risk assessment undertaken was narrow in focus (Child A's had not received primary immunisations). This could have been used to further explore wider issues regarding why the family were not engaging with some health services. This brings into question the effectiveness and delivery of the supervision model.*

- 3.6 In Child A's third year, Child A had a colostomy and was referred for an endocrine review. It was reported by mother that Child A had developed oral aversion; an avoidance or fear of eating, drinking, or accepting sensation in or around the mouth. There is no evidence this was observed by any health practitioner.
- 3.7 Child A continued to gain no weight. Increasingly, Child A was not being taken to hospital appointments by the parents. Referrals were made for joint adult and child occupational therapy and Child A was referred for educational assessments.

#### ***Appraisal of Professional Practice***

*Despite supplementing Child A's feeds with different nutritional supplements, weight gain did not improve. A pattern of behaviour continued whereby professionals did not take a step back to question the underlying cause for the poor weight gain culminating in a drift in clinical care. The dietician reported to the independent reviewer that now they would admit a child for a two week observation period and any parental resistance would result in a child protection referral. The Paediatric consultants report that there are now protocols in place to enable children who are small for gestational age to be eligible to receive growth hormone.*

*Despite Child A's mother cancelling multiple physiotherapy and occupational therapy appointments, this did not trigger any safeguarding response. Cancelled and postponed appointments went unchallenged, with no consideration to the*

*adverse effect on Child A's mobility and whether this constituted a potential safeguarding concern.*

*The review identified that at the time, the policy regarding children who were not taken to occupational therapy appointments was not so stringent and as the reasons for appointments being postponed seemed legitimate, the family were never challenged.*

*The review heard that in the context of practice today, the therapist would ring the primary therapist to get a 360 degree picture and undertake a deeper risk analysis. Whilst acknowledging this position, the review covers a period of time from 2006, when the safeguarding needs of children with significant health needs and disabilities were well established across the health sector. This can be seen from the publications and professional health guidance in 2004 and 2009.<sup>8 9</sup>*

3.8 In Child A's fourth year, weight fluctuated and ultimately, Child A only gained 0.5kg. Mother reported that Child A was now experiencing urinary retention. Further tests were undertaken, including a genetic assessment, chromosome assessment and skeletal survey. Following endocrine testing Child A commenced treatment with growth hormone. Child A's mobility decreased, and a wheelchair was prescribed.

3.9 Child A was also referred for a statutory educational assessment and it was agreed that Child A's educational placement would commence in September 2011. The identified school was for pupils with physical disabilities and additional sensory needs. In February 2011 however, Child A's parents began to express a view that home tuition (as distinct from Elective Home Education<sup>10</sup>) would be better able to meet Child A's particular needs. In April 2011, Child A's parents made a formal complaint to the Local Authority's education services concerning poor communication with the family and delays in agreeing an appropriate

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<sup>8</sup> [https://www.cqc.org.uk/sites/default/files/documents/safeguarding\\_children\\_review.pdf](https://www.cqc.org.uk/sites/default/files/documents/safeguarding_children_review.pdf)

<sup>9</sup> The National Service Framework for Children (2004) states that: Children or young people failing to attend clinic appointments "may trigger concern, given that they are reliant on their parent or carer to take them to the appointment. Failure to attend can be indicator of a family's vulnerability, potentially placing the child's welfare in jeopardy."

<sup>10</sup> Home tuition is an alternative to education in school provided by the Local Authority

placement for Child A. The response acknowledged some shortcomings, although the parents chose to escalate their complaint further, citing the response to be insufficient. On further investigation, this again acknowledged that communication could have been improved.

#### ***Appraisal of Professional Practice***

*Wheelchair services are a secondary service and support the work of therapy services. Given reported professionals concerns regarding the impact on Child A's mobility should a wheelchair be prescribed, this would suggest that the assessment and approving its provision was not as comprehensive as it should have been. Both occupational therapy and the wheelchair service should have taken a broader, more holistic approach in order to ensure that Child A's mobility was not compromised.*

*The wheelchair service believed they were prescribing the wheelchair to aid Child A's independence and to assist mother in coping given her health issues.*

3.10 In Child A's fifth year, due to poor weight gain, Child A was admitted to hospital (1) for a Hickman line insertion<sup>11</sup>. This would allow Child A to commence Parental Nutrition<sup>12</sup>. Child A underwent surgical intervention in respect of reported urinary problems (Clean Intermittent Catherization<sup>13</sup> (CIC) which culminated in the formation of a Mitrofanoff<sup>14</sup>). Due to complications with Child A's PEG Jejunostomy, the hospital stay was extended. Child A was ultimately discharged home after a five-month admission. It should be noted that the prolonged hospital stay should have triggered a referral to Children's Social Care under Section 85 of the Children Act.

3.11 Whilst in hospital (1), Child A was prescribed an opioid (Fentanyl) for pain relief. Child A continued to be prescribed Fentanyl following discharge home, although there was no documented plan for following up on pain management. At the time,

<sup>11</sup> A Hickman line is a long, thin, hollow tube that goes into a vein in the chest.

<sup>12</sup> Parental Nutrition is the feeding of specialist nutritional products to a person intravenously, bypassing the usual process of eating and digestion

<sup>13</sup> Clean intermittent catheterisation is a way of emptying the bladder of urine if passing urine is difficult or impossible. It involves passing a catheter (thin, plastic tube) through the urethra into the bladder

<sup>14</sup> The Mitrofanoff procedure is a surgical procedure in which the appendix is used to create a conduit between the skin surface and the urinary bladder

the parents were asked if they would like a referral to Children's Social Care for ongoing support. This was declined and no referral was made.

- 3.12 On discharge, the CCNT was asked by the hospital (1) to take blood from Child A on a weekly basis and to monitor blood pressure three times weekly. Due to the prolonged hospital admission, Child A missed the first two terms of planned education and commenced school in April 2012.

#### ***Appraisal of Professional Practice***

*Child A was discharged home with a continuing prescription of Fentanyl. There was no plan for follow up or how Child A would be weaned off this opioid. Child A had eight further admissions whilst on Fentanyl, but no concerns were raised regarding its use.*

*Child A was not referred back to the hospital pain team by the paediatric gastroenterologist who preferred to manage his own patients, thus isolating them from a wider professional perspective. If Child A had been referred to a pain team, they may have been able to raise concerns regarding the prescribing.*

*During a hospital (1) admission, despite nurses identifying concerns regarding how much Fentanyl Child A was taking, they did not escalate their concerns. Furthermore, the review found no evidence of professionals discussing mother's own use of opioids for pain management and the impact that this might have had on her parenting capacity of Child A or the family's views about their use. An open dialogue with Child A's parents by their GP could have been beneficial to explore this issue.*

*The CCNT is an expensive resource and yet the financial impact of acting as 'couriers' to transport blood and blood pressure readings was not questioned by themselves or others. The impact of this is likely to have been unnecessary pressure on the system and availability of the CCNT resource to other families.*

- 3.13 In Child A's sixth year, mother continued to report that Child A was experiencing symptoms of abdominal bloating, pain, retching and vomiting. It is unclear how many of these symptoms were ever witnessed by health professionals. During interaction with the gastroenterology clinic, Child A's mother reported further medical problems (including Left Ventricular Hypertrophy<sup>15</sup>).
- 3.14 The clinic did not know who had made these apparent diagnoses. Mother also reported that Child A required increasing doses of Fentanyl. Referrals were made to the renal team and ophthalmologist.

***Appraisal of Professional Practice***

*The CCNT raised concerns with a consultant regarding the amount of Fentanyl that Child A was taking, although failed to follow these up. Similarly, Child A's GP continued to prescribe Fentanyl despite their own professional concerns and escalation to the same consultant. There was no escalation through safeguarding channels.*

*In turn, the community pharmacist did not question the repeated prescriptions for Fentanyl for a child. There was an opportunity for discussion between the community pharmacists and GP, although there is no evidence these discussions occurred.*

*Child A's mother was noted to interpret and identify when Child A was in pain. Professionals were not convinced Child A was in pain, but did not challenge or raise concerns regarding this.*

- 3.15 In Child A's seventh year, health practitioners reported continuing cancellation of appointments. Child A was said by mother to be suffering from increased pain and Fentanyl use increased. Child A always attended school sitting with mother, which limited Child A's ability to engage in educational activities. School attendance continued to be poor and the family had concerns regarding how Child A's medical needs were being met at school. Ultimately home tuition was agreed.

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<sup>15</sup> Left ventricular hypertrophy is enlargement and thickening (hypertrophy) of the walls of the heart's main pumping chamber (left ventricle).

- 3.16 Between May 2013 and July 2017, the alternative educational provider was commissioned by the Local Authority's Special Educational Needs (SEN) department to deliver one hour of education per day to Child A at home. The alternative education provider employed an unqualified teacher to provide Child A's education.
- 3.17 During this time Child A was not on the Alternative Providers roll. Child A was taking medication to manage pain, which reduced engagement in educational activities due to the sedation effect. Because of this, Child A's academic progress varied and whilst some progress was made, this was below expectations due to frequent absences for poor health.
- 3.18 Mother was managing all of Child A's care, including medication and intravenous feeds. Child A was transferred to another consultant. He noted that Child A was presenting with joint pain and swelling and suggested Child A may have a syndrome affecting connective tissues, *Ehlers Danlos Syndrome Type 3*. However, this was never confirmed by a rheumatologist which would be usual practice.

***Appraisal of Professional Practice***

*In view of Child A's significant health needs, one hour of education was provided per day. The assumption, following discussion with Child A's parents, was that Child A wouldn't cope with more than this. In practice, Child A often did not even have an hour a day, as at times Child A was said to be in pain, or was asleep for part of that hour when the tutor was present. There was very little external monitoring of the regularity of the input or reviews of the amount of tuition that could be put in place.*

*There was a lack of professional challenge to the parents wanting Child A to have home tuition, which culminated in Child A having a minimal number of hours of education allocated and isolating Child A from their peer group.*

*Furthermore, despite Child A's significant health needs, it was deemed acceptable for an inexperienced and unqualified teacher to support Child A's education at home. The SEND 2015 code of practice<sup>16</sup> states that 'In line with local authorities' duty to arrange suitable education as set out above, children and young people who are in hospital or placed in other forms of alternative provision because of their health needs should have access to education that is on a par with that of mainstream provision, including appropriate support to meet the needs of those with SEN. The education they receive should be good quality and prevent them from slipping behind their peers. It should involve suitably qualified staff who can help pupils progress and enable them to successfully reintegrate back into school as soon as possible.'*

*Child A was given a potential diagnosis of Ehlers Danlos 3 which was not confirmed by rheumatology assessment and potentially hindered professional assessment and recognition that Child A's immobility and joint pain was due to prolonged disuse.*

*The parents did not take Child A for the rheumatology assessment to have the diagnosis of Ehlers Danlos confirmed. Professionals neither questioned why they had not brought Child A, nor considered the impact because of this. An unreliable diagnosis and associated 'label' can have a detrimental impact on future decision-making regarding care.*

- 3.19 In Child A's eighth year, the CCNT continued to undertake blood pressure monitoring at home. Mother made repeated requests for prescriptions for Fentanyl.
- 3.20 Following concerns raised by the CCNT and GP about Child A's Fentanyl use, a multi-agency meeting was held which culminated in an assessment being undertaken by the hospital (3) safeguarding team. No specific safeguarding concerns were identified, rather there was concern regarding a lack of education and home medication. At the same time there was dialogue between one of Child

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<sup>16</sup> [SEND Code of Practice 2015](#)

A's consultants and the GP as to how much Fentanyl Child A should be prescribed. The consultant reassured the GP that, whilst Child A's pain was 'problematic', the prescription was needed.

- 3.21 The CCNT's concerns were followed up separately by another consultant who telephoned Child A's mother. Mother was reported to have said that Child A had complex needs, but was well monitored, seeing lots of consultants, and would call if she needed anything (as Child A was reported as being too unwell to see the consultant at the time).
- 3.22 A plan was made to see Child A in a few months. Following the consultant's telephone call, an e-mail was sent by this consultant to her counterpart expressing concerns for Child A's management and safeguarding concerns. It is not clear what the outcome was as there is no documented update.

#### ***Appraisal of Professional Practice***

*Despite the GP and CCNT having concerns regarding the use of opiates, Child A remained on this medication for another three years. The GPs were under the belief that Child A would be assessed by a chronic pain team and so continued prescribing the opiates and any concerns they held were downgraded. However, these were false reassurances as Child A was never seen by the pain team.*

*In the opinion of the review, the GPs were influenced by the hierarchy of medical professionals and felt bound to prescribe a medication prescribed by a specialist paediatrician (The serious impact of withholding or stopping this prescription, such as acute opiate withdrawal, pain and suffering, is also likely to have contributed to the reasons this was continued). The GPs identified concerns for Child A became secondary in their decision making. They failed to follow safeguarding procedures, placed an over-reliance on the safeguarding practice at the hospital (3), and despite their continued anxiety about the Fentanyl prescriptions, did not follow these through.*



*Given the increasing number of appointments either cancelled, postponed or missed, neglect should also have been considered. There was a failure to apply policies, failure to see the child's perspective, failure to communicate and to work together. No one took ownership and acted on behalf of Child A. Record keeping was also poor and further hindered evidence of concern for Child A's wellbeing. It appears that there was reluctance or lack of confidence to make a social care referral.*

*The review identified a number of examples where practitioners did discuss Child A in safeguarding supervision, but subsequent actions were insufficient in their focus. There was a lack of connection between clinical and safeguarding supervision and supervision did not appear to promote and ensure safe practice.*

3.23 Between the ages of eight and nine, Child A was referred to hospital (2) for a pain assessment, although was not taken to the appointment. Child A had increasing lack of mobility and was now totally reliant on a wheelchair. Mother was seeking home adaptations for hoisting. In November 2016 attempts were made to carry out a joint visit with adult occupational therapist services to support mother in caring for Child A and the consideration of home adaptations. There were challenges in arranging this.

3.24 Mother declined consent for the occupational therapist to contact the GP and it was not until the occupational therapist informed mother that Child A would be discharged from the service that an appointment was agreed. However, when this took place, Child A was reported as being unwell shortly after the occupational therapist's arrival. Specialist hoisting was eventually put in place in May 2017, though this was removed later in the year.

#### ***Appraisal of Professional Practice***

*The concerns of healthcare professionals regarding Child A's response to treatment and not being brought to appointments should have been escalated as possible indicators of neglect.*

*The family's repeated failure to take Child A for review by the pain team between 08/06/2016 & 27/06/2017 is seen as significant in this context due to the many side effects Child A was presenting with. These missed appointments also contributed to the delay in Child A being weaned off the opiates.*

*Mother declined consent for occupational therapy to contact the GP regarding adaptations to the home and this appears also to have gone unchallenged without discussion as to why mother would not want the GP to be able to contribute to the assessment. Good practice requires that health services communicate with each other.*

- 3.25 From the ages of nine to ten, Child A continued to take Fentanyl for pain management via patches and lozenge. Child A was now reported to be totally reliant on mother for all aspects of physical care.
- 3.26 The impact of opioid dependency was discussed with mother and Child A was referred for assessment with the chronic pain team at hospital (2). Mother did not take Child A for this appointment. Throughout the year, mother either cancelled or failed to take Child A to any outpatient appointments.
- 3.27 A discussion took place between the occupational therapy team and the hospital (3) safeguarding team who suggested further assessment of the package of care and a referral to the Children's Social Care disability team if the package of care required review. A referral was never made and neither was there escalation of safeguarding concerns given the number of appointments Child A was not taken to.

#### ***Appraisal of Professional Practice***

*The occupational therapist raised concerns with the safeguarding team at the hospital (3) who advised further assessment, rather than using the information already presented to make a referral to children's social care. At this point there is enough concern to prompt the safeguarding team to consider developing a chronology and holding a professionals meeting. Professionals did not appear*

*confident in the safeguarding policy and procedures and consequently there is a loss of sight of Child A.*

*Despite concerns about Child A's opioid dependency no decision is made with regard to how to wean Child A off the Fentanyl. This is a significant safeguarding risk which is not addressed and another example of Child A being neglected.*

- 3.28 In Child A's 11<sup>th</sup> year, occupational therapy offered a referral to psychology due to a few turbulent months with multiple bereavements. Mother declined these as she felt the family were supporting each other.
- 3.29 There were increasing concerns regarding Child A's use of Fentanyl and following a pain clinic review and a multi-disciplinary meeting of health practitioners, Child A was admitted to hospital (1) in July 2017. The admission was co-ordinated to wean Child A off Fentanyl, to provide intensive physiotherapy (to help Child A begin walking again) and to engage Child A with occupational therapy to focus on oral aversion.
- 3.30 At the same time, a referral to Children's Social Care was made regarding concerns about possible Fabricated or Induced Illness (FII). Following a child protection investigation, FII was not substantiated. Child A was, however, placed on a Child In Need Plan. In late 2017, Child A had successfully weaned off the Fentanyl and was discharged home with a comprehensive multi-disciplinary plan.
- 3.31 It is important to document that despite significant health needs, Child A wasn't prioritised for an Educational Health and Care Plan (EHCP) under the 2014 SEND reforms and wasn't transferred onto an EHCP until November 2017 following admission to hospital (1).

#### ***Appraisal of Professional Practice***

*The plan to admit Child A to hospital(1) in July 2017 is the first real indication of practitioners understanding and proactively responding to Child A's over medicalisation. Hypothesis about possible FII were rightly considered based on*

*Child A's presentations and that of the family, recognising that FII can exist alongside established medical conditions. A referral was made to Children's Social Care in line with expected procedure. This was good practice.*

*A child protection enquiry under Section 47 of The Children Act 1989 was appropriately triggered given the nature of the concerns. Whilst the overall outcome was that FII was not substantiated (in that FII could neither be proved nor disproved), the SCR identified a number of weaknesses in this intervention. For example, Children's Social Care did not contact key health professionals involved with Child A for a view of their involvement. It is significant to note the context of the complex and fragmented health network, however in November 2017 joint health leads were appointed. Of significance to the referral itself, when the request was made for a medical opinion in relation to FII, this was neither provided nor subsequently escalated.*

*Child A was also not seen on their own as part of the child protection enquiry. Social workers were persuaded by the parents that due to Child A's complex healthcare needs they needed to be present. This was accepted with no challenge to the parents or discussion with healthcare professionals. Not to see a child alone is poor practice and compromises a comprehensive assessment where the child is at the centre. The London Child Protection procedures set out that 'The children, who are the focus of concern, must be seen alone, subject to their age and willingness, preferably with parental permission.'*

*Child A became lost in the education system due to a lack of capacity to monitor the database of children. At the time of the review, the Local Authority's Education Service reported that it was not assured that all children were receiving annual reviews. The review identified contradictory evidence as to when Child A was taken off roll from school prior to commencing alternative home tuition. This lack of clarity further emphasised the absence of robust systems and processes in place at the time.*

## 4 Child A's Voice in the Review

4.1 Child A was seen alone by the independent reviewer and chair of the review panel. The parents were in another room, although all doors were open so they could hear the conversation and respond to any requests from Child A.

- Child A was very chatty and discussed a variety of topics including favourite books, games and politics. Child A was keen to show us some plants on the balcony, although mother was not happy for Child A to go outside, so instead Child A pointed to various plants. Child A said they wanted to be a blood pressure nurse when older.
- At one point, Child A wanted to show their ability to walk. Child A wrapped their arms around mother for support, rising to a standing position and walking around the room. Child A was excited to show they could take sips of water from a glass. This was a very recent development.
- It was evident as the conversation progressed that if it strayed anywhere near a discussion about healthcare, Child A would say immediately *'I don't know, you need to ask my mother'*.
- Child A's mother was very attentive during our visit, checking if Child A was happy for her to leave, checking Child A did not feel too tired and suggesting Child A might only want to talk for about 20 minutes. We ended up talking with Child A for at least an hour.

## 5 The Voice of Child A's Parents in the Review

5.1 The independent reviewer and chair of the review panel met with Child A's parents on four occasions. Both expressed a hope that the SCR will allow professionals to think '*could we have done it differently?*' They believe there is scope for '*huge learning across the board*'. They identified the following as the most pertinent issues for them in respect of the care afforded to their child:

- Child A's prematurity and ongoing health needs.
- A shifting diagnosis and the parents never really being clear what it was.
- Child A not feeding well, not gaining weight and periods where Child A was tiring very quickly.
- They felt psychologically dependent on the Fentanyl as it meant they could do something to stop the pain.
- Too many professionals involved and poor communication with the family and between professionals.
- They felt caught in the middle with each professional thinking their view carried more weight and not listening to what the family said.
- The biggest issue was that of communication between hospital and community and the impact this had on the family in terms of the care for Child A i.e. the prescribing of Fentanyl.
- They needed an advocate who would not be swayed by a particular professional background and referenced a similar service in Manchester.
- Mother said she felt she had no choice but to co-ordinate care from the outset. She was managing and co-ordinating appointments from different hospitals, all the equipment and stock (which was observed to be extensive around the home).
- Child A's parents emphasised that whilst '*mother*' was ordinarily noted as either attending, cancelling or postponing appointments, these were joint decisions made by both parents.

- Child A's parents also said they knew other families who are going through safeguarding intervention similar to that with Child A. They expressed a view that child protection investigations undertaken in these contexts '*should identify systemic failures and not Fll and that professionals have to reflect on their own actions*'.
- They continue to feel vulnerable as Child A is still receiving services, professionals are still practising and that they are '*protecting themselves*'. They believe they are a '*red flag with Children's Social Care*'.

## 6 Analysis, Findings and Recommendations

6.1 The following sections of the report provide an analysis of the professional practice based on a range of identified themes. Where relevant, this includes a focus on why relevant decisions were taken by practitioners, a critique of how agencies worked together and any shortcomings in this context. At the end of each section, the SCR identifies what professionals and/or their organisations need to do differently and what needs to happen to ensure that agencies learn from this case.

### 6.2 The Voice of Child A

*Article 12 UNCRC: every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously.*

6.3 Throughout the professional intervention with Child A, there has been insufficient consideration of the child's individual voice. The review identified that Child A did not have the opportunity to express their own views and opinions. In all aspects of Child A's life and care, mother spoke for her child. In some instances, professionals reported that when Child A was younger, mother would ordinarily answer any questions and once older, Child A would defer to mother, rather than answering for themselves.

6.4 In other circumstances professionals did not seek to see Child A alone, which would have provided the opportunity for Child A to express themselves. Child A's 'lack of voice' to say how they were feeling may have had a significant impact on treatment, especially pain management.

6.5 Of equal importance is that Child A's mother is reported by some professionals as being reluctant for Child A to be seen alone and when Child A was, she was in an accompanying room. Child A's mother was able to hear all that was asked and what was talked about.



- 6.6 The review identified that very few professionals actually saw Child A on their own. The exception to this was the consultant clinical psychologist, although this was under the conditions described above. The rationale provided by Child A's mother was that she needed to be present to manage Child A's healthcare needs. This position has been insufficiently challenged.
- 6.7 During the child protection enquiry, mother would not let Child A be seen alone. The rationale provided by Child A's mother was the same as that provided to other practitioners. The social workers accepted this explanation, despite this not meeting the expected standards of practice as set out in the London Child Protection Procedures<sup>17</sup>.
- 6.8 Both of the involved GPs told the review that it was difficult to interact with Child A and that they found mother a barrier to this. As an example, during the first home visit, mother said Child A was asleep, although the GP thought that Child A only had their eyes closed and was 'obviously' awake'. On the second home visit, mother kept putting headphones on Child A if the discussion involved hospitals or medical conditions. This made it very difficult for the GPs to get to know Child A and ensure they understood their needs and feelings.
- 6.9 Hearing the voice of the child has been a recurrent theme in many SCRs and was the subject of an Ofsted thematic review<sup>18</sup>, published in 2011 and a CQC report<sup>19</sup> in 2016. It is part of safeguarding training and established good practice. However, the absence of Child A's voice neither raised concerns in a safeguarding context nor prompted further professional curiosity. Practitioners were too ready to accept what Child A's mother said on behalf of her child.
- 6.10 Within the context of a child protection investigation, managerial oversight within Children's Social Care should always ensure that there is clear evidence about

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<sup>17</sup> 3.7.1 The children, who are the focus of concern, must be seen alone, subject to their age and willingness, preferably with parental permission. London CP Procedures 5<sup>th</sup> Edition 2017

<sup>18</sup> The voice of the child: learning lessons from serious case reviews, Ofsted, April 2011

<sup>19</sup> Not Seen, Not Heard, A review of the arrangements for child safeguarding and health care for looked after children in England, CQC, July 2016

how a child's views, wishes and feelings have been adequately and appropriately secured during this process.

**6.11 Finding 1: Practitioners did not consistently listen to the voice of Child A so as to understand Child A's perspective, concerns and feelings in order to undertake a meaningful assessment.**

**6.12 What Needs To Be Done Differently**

- All practitioners should caution against relying solely on information provided by a parent and ensure that the child's views are sought directly.
- Practitioners from all disciplines should highlight as a matter of concern if a parent is obstructive when seeking to hear the voice of a child. Supervision should be used as one of the mechanisms through which practitioners can escalate their concerns and determine the next steps in this respect.
- All children should be fully engaged by health practitioners in their care and treatment and supported to gain an age appropriate understanding of the treatment they are receiving.

**Recommendation 1:** The CHSCP should promote the voice of the child and ensure that the importance of communicating with all children and young people, including non-verbal communication, so that an understanding of their lived day to day experiences can be gained, is embedded in all procedures and training provided.

**Recommendation 2:** The CHSCP should request that health providers undertake an audit of paediatric community and inpatient records to ensure that children have been involved in an age appropriate way at each stage of their care planning, and had their views listened to and considered. The report and associated learning should be presented to the CHSCP.

**Recommendation 3:** The CHSCP should review existing multi-agency guidance to ensure this is sufficient in defining the circumstances when children should be seen alone.

**Recommendation 4:** The CHSCP should establish assurance from safeguarding partners and relevant agencies that there are sufficient mechanisms in place to identify when a child's voice is not being sufficiently heard as part of professional intervention.

### 6.13 Assessment, Intervention and Treatment

#### 6.14 The Lack of Objective Assessment and the Over-Medicalisation of Child A

*Article 3 UNCRC: the best interests of the child must be a top priority in all decisions and actions that affect children.*

*Article 24 UNCRC: every child has the right to the enjoyment of the highest attainable standard of health.*

6.15 In the context of the significant involvement with Child A by a range of health practitioners, there was a lack of objective assessment when deciding on proposed treatment. Child A presented with (and mother presented her child with) complex medical problems, which different professionals understood from their own particular disciplines. The review has seen no evidence of a holistic medical overview. Individual medical practitioners appear to have treated Child A's symptoms as they saw fit.

6.16 The SCR identified that mother began reporting her concerns regarding Child A's health from a very early stage. The response by medical professionals was to unreservedly accept what Child A's mother was saying and to respond by investigating and treating the reported symptoms, rather than considering and testing alternative possibilities. Treatment included significant medical interventions for poor feeding, lack of weight gain, bowel problems and later urinary retention and pain.

- 6.17 However, as symptoms persisted there is little evidence that healthcare professionals sought to witness these or examine Child A's response to treatment directly. When healthcare professionals did attempt to assess Child A, mother was reported to resist engagement on account that Child A was in too much pain.
- 6.18 For example, despite extensive reviews and changes to the nutritional regime, Child A's weight gain failed to improve, and at no point was it suggested that Child A should be admitted in order to observe feeding. Furthermore, after mother reported that Child A was not passing urine for up to 16hrs, clean intermittent catheterization (CIC) was commenced. Soon afterwards, mother reported she could not continue to undertake the CIC due to bladder spasms. In response, a Mitrofanoff was made. Child A now has a Hickman line, Mitrofanoff stoma<sup>20</sup> and jejunostomy stoma<sup>21</sup>.
- 6.19 This approach to healthcare has been well documented; *'Reliance on carer reports of history and diagnoses, and accepting the carer as a conduit of medical information is based on paediatricians' default assumptions regarding parents' truthfulness and reliability - 'mother knows best', This leads to repeated investigations and treatments'*<sup>22</sup>.
- 6.20 The lack of professional challenge and curiosity in this respect culminated in the ongoing medicalisation of Child A. Child A has been the subject of significant medical labelling, with interventions from birth recognised as having a substantial impact on Child A's life. There remain questions as to whether all of these interventions were needed.
- 6.21 The SCR identifies a number of issues influencing the professional response in this context, including a possible fear of challenge to an assertive parent (seen as 'challenging'), a fear of having difficult conversations and a fear of hierarchy (and challenging the decisions / actions of senior health staff). Ultimately, it may also have been easier for health practitioners to medicalise Child A as this was known

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<sup>20</sup> A stoma is an opening on the abdomen that can be connected to the digestive or urinary system to allow to be diverted out of the body.

<sup>21</sup> A jejunostomy is an extension of the gastrostomy feeding tube through the stomach into the small bowel.

<sup>22</sup> 40 years of fabricated or induced illness (FII): where next for paediatricians? Paper 1: epidemiology and definition of FII. Davis P et al *Arch Dis Child* Feb 2019 Vol 104 No 2 <http://dx.doi.org/10.1136/archdischild-2017-314319>

territory for them. This approach is unhelpful and potentially harmful for both the child and the parent/carer.

6.22 As part of the internal review of the paediatric gastroenterology department, a number of other children were identified who were also given an unsubstantiated diagnosis, experienced a lack of regular review and were receiving ongoing medical interventions and treatment.

6.23 The review learnt that the complex health needs of some children present some gastroenterologists with challenging problems in identifying the causes of a range of symptoms and pain. Sometimes this can lead to an overly medicalised approach of diagnosis, without sufficient attention to emotional components to the experience of pain for both child and carers.

6.24 In respect of Child A, one of the consultants made a potential diagnosis of *Ehlers Danlos 3* (without proper assessment). This served to explain Child A's increasing immobility. However, when 11 years old, Child A was assessed by a paediatric rheumatologist at another hospital (2). At this point, it was clarified that Child A did not have *Ehlers Danlos 3* and therefore had the potential to improve. The news that Child A could do more was reportedly met with shock by the parents, who had believed Child A had reached their limit of capability.

6.25 Child Abuse and Neglect in a Medical Context

*Article 19 UNCRC: all children have the right to protection from all forms of violence, abuse, neglect and mistreatment by their parents or anyone else who looks after them.*

6.26 The referral of Child A to Children's Social Care for concerns about suspected Fabricated or Induced Illness (FII) was justified on the basis that many of the identified features of FII were evident. It is pertinent to note that many of Child A's presentations are identified in the work by Glaser et al.<sup>23</sup>

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<sup>23</sup> For debate: Forty years of fabricated or induced illness (FII): where next for paediatricians? Paper 2: Management of perplexing presentations including FII Danya Glaser,<sup>1</sup> Paul Davis<sup>2</sup>

- Symptoms not observed independently in their reported context.
- Symptoms not corroborated by the child.
- Reported symptoms or observed signs not explained by child's known medical condition.
- Inexplicably poor response to medication or procedures.
- Repeated reporting of new symptoms.
- Frequent presentations, seeking opinions from multiple doctors but often with paradoxically poor compliance with medical advice and multiple failed appointments.
- Carer(s) insistent on more, clinically unwarranted, investigations, referrals, continuation of or new treatments.
- Restriction of child's daily life and activities that is not justified by any known disorder, possibly including the use of wheelchairs and other aids.

6.27 There has been a debate for many years regarding the terminology of FII, previously termed *Munchhausen by Proxy*. Fabricated illness is defined as occurring when '*the child receives unnecessary or harmful medical care at the instigation of a caretaker*'.<sup>24</sup> This is unhelpful in two ways:

- Firstly, investigation focus on establishing the culpability of the parents, rather than on the well-being of the child.
- Secondly, the label suggests to all practitioners that the illness is fabricated and distracts from the profound biological effects of this form of maltreatment. The child we see is genuinely and extremely unwell.

6.28 In the USA the term '*Medical Child Abuse*' (or '*Child Abuse in a Medical Context*') is now accepted. This provides for an improved focus on the child in that the identity or motivation of the responsible adult is secondary to the fact of abuse.

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<sup>24</sup> Fabricated or Induced Illness by Carers (FII): A Practical Guide for Paediatricians. Royal College of Paediatrics and Child Health (RCPCH) 2009

- 6.29 Many health practitioners feel deep unease about the term '*Medical Child Abuse*'. This is understandable, but there is a clear need to acknowledge that in seeking to do what is best for children, medics can also unintentionally cause serious harm to them. The acknowledgment and recognition of this fact by health professionals is a required first step in effectively managing such cases.
- 6.30 The term '*perplexing presentations*' is also considered by the SCR as similarly unhelpful. Whilst accurately describing features of the child's illness and challenging parental behaviours, asking practitioners to be perplexed is not a recipe for diagnostic clarity or timely intervention.
- 6.31 Where the problem is '*over-medicalisation*' (including both over-diagnosis' and 'over-treatment'), this should be stated clearly by medical practitioners. In the opinion of the SCR, "*over-medicalisation*" should replace the term '*perplexing presentation*'. It more appropriately refers to the state of the child's health as opposed to the state of mind of the doctor.
- 6.32 Despite the context of the referral to Children's Social Care, the review identified that practitioners did not actually believe that FII was evident, but rather that Child A was subject to child abuse in a medical context. FII was the 'best fit'. However, the referral itself potentially distracted professionals from trying to better understand the underlying issues and root cause of Child A's '*perplexing presentations*'.<sup>25</sup> It diverted them from looking more closely at the possibility that Child A may have been subject to medical harm as a consequence of invasive investigations and treatments.
- 6.33 From a medical perspective, accepting that treatment may not have been necessary may be difficult for professionals to come to terms with. There is an underlying question about how easy it would be for professionals to say, '*I don't know*' and not provide treatment. How would the medical world and society view and accept this position? There is also a genuine question about the costs of

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<sup>25</sup> Glaser D, Davis P. ADC Online First, published on April 4, 2018 as 10.1136/archdischild-2016-311326

overdiagnosis<sup>26</sup> and the need to develop further guidance on the de-medicalisation of care.<sup>27 28</sup>

6.34 There has also been professional resistance to recognising the clustering of such cases around particular paediatric units (Child A was one of twelve children identified by the hospital (1)) and particular new diagnostic labels (Child A was misdiagnosed with Ehlers-Danlos Syndrome hypermobility type)<sup>29</sup>. There is a need for health services to have in place clear systems where such clusters or routine / frequent misdiagnoses can be promptly identified. Children in these contexts can potentially be at risk from extra-familial harm as a consequence of the treatment they are receiving.

**6.35 Finding 2: Child A's reported symptoms were responded to without objective assessment. This led to unnecessary or inappropriate medical intervention being undertaken.**

### **6.36 What Needs To Be Done Differently**

- All healthcare practitioners should ensure their practice is proportionately based on fact and that reported symptoms presented by a parent are triangulated through observation and investigation. Practitioners need to consider when standard interventions are failing.
- All practitioners need to maintain 'respectful uncertainty' and professional curiosity where concerns for the child emerge over a period of time.
- If a parent obstructs assessment of their child in the pursuit of medical assessment and diagnosis, professionals should seek safeguarding consultation.

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<sup>26</sup> £130,000 were spent on Fentanyl prescriptions for Child A, and ongoing costs of intravenous nutrition and other interventions were very significant.

<sup>27</sup> The Royal College of Paediatricians and Child Health is currently consulting on revised guidance which focusses on Perplexing Presentations / FII. And it would be helpful for this SCR to be considered as part of the consultation.

<sup>28</sup> Guidelines for the diagnosis and treatment of growth hormone deficiency state that great care should be taken to prevent confusion with psychosocial stress and consequent overdiagnosis and treatment, but there is no published guidance on how to proceed if concerns are raised about a child who is already being treated.

<sup>29</sup> The overdiagnosis of Ehlers Danlos Syndrome hypermobility type has been such a serious problem in UK paediatric practice that the RCPCH has produced a position statement <https://www.rcpch.ac.uk/resources/establishing-correct-diagnosis-ehlers-danlos-syndrome-hypermobility-type-heds-children>



- Psychological stress to the child and the profound accompanying biological effects should be recognised when considering children who have been over-medicalised and considered as part of the clinical pathway.
- Practitioners should ensure they seek safeguarding supervision where they have concern for ‘cases that don’t make sense’.

**Recommendation 5:** The CHSCP should be sighted on and seek assurance that the recommendations of the internal review undertaken within one of hospitals involved with Child A have been implemented. This should cover reassurance that practice includes direct observation by clinicians has been built into clinical pathways.

**Recommendation 6:** The London Safeguarding Children Partnership should review its practice guidance on Fabricated and Induced illness to ensure it appropriately takes account of children who are coming to harm through excessive medical intervention and references the revised policy of the RCPCH on perplexing presentations.

**Recommendation 7:** The CHSCP should ask the RCPCH to review their pathway for children who are over-medicalised (*‘perplexing presentations’*) to ensure it includes the impact of psychological stress.

**Recommendation 8:** The responsible commissioner for the wheelchair service should assure the City & Hackney CCG that there is sufficient practice guidance for children who are confined to a wheelchair in the absence of an accepted medical diagnosis.

**Recommendation 9:** The City & Hackney CCG should seek assurance that protocols for nutritional rehabilitation where there is no demonstrated gastrointestinal disease have been developed and are used in clinical practice.

**Recommendation 10:** The City & Hackney CCG should seek assurance that where it is agreed that a rehabilitation program is required because of over medicalisation, clinical leadership is provided by a general paediatrician with safeguarding expertise as part of a multi-disciplinary team.

**Recommendation 11:** The City & Hackney CCG should ensure there is better collaboration and communication between secondary and tertiary care with local processes in place to identify when overmedicalisation / misdiagnoses of children is clustered within a single paediatric department.

### 6.37 The Management of Pain

*Article 24 UNCRC: every child has the right to the enjoyment of the highest attainable standard of health.*

- 6.38 Following a long and difficult hospital (1) admission when Child A was five years old, pain was managed through the prescription of an opioid, Fentanyl. At the point of discharge, Child A was still perceived to be experiencing significant pain and it was decided that Child A should be discharged on this analgesic. Over the next six years, no professional was overseeing Child A's pain management or the impact of long-term opioid use on the child's health and activities of daily living.
- 6.39 The SCR identified that once Child A was discharged, the team responsible for acute pain management at hospital (1) no longer held responsibility in the community. There was (and still is) no provision for monitoring and supporting children in the community with chronic pain.
- 6.40 The SCR further identified that the limited communication between the GP and Child A's consultant (alongside mother's reporting that she was in contact with the consultant) meant that the GP was falsely reassured that it was acceptable to continue prescribing the Fentanyl. This reassurance was maintained even with mother asking for increasing amounts.

- 6.41 Child A experienced the significant side effects of Fentanyl which were compounded by further prescribing. When Child A was 11 years old, a multi-disciplinary meeting was held and it was determined that Child A should be admitted to hospital (1) to be weaned off the opiates. This was successfully achieved.
- 6.42 The initiation of the Fentanyl prescribing for Child A, without clearly addressing the cause of pain, was compounded by the lack of overview of opiate prescribing after discharge. A discharge letter from Child A's first admission had a very clear plan for follow up of all of Child A's medical problems, with the single exception of the opiate prescribing.
- 6.43 Multiple clinicians have recorded that Child A was on long term Fentanyl, although from the documentation, it is unclear if everyone was aware that this included continuous patches as well as lozenges. There was a lack of clarity in the records as to who was overseeing the opiate prescription.
- 6.44 Some clinicians documented that Child A was under the care of the pain team, but there is no evidence that this was the case in the outpatient setting. During any admissions, whilst Child A was always actively reviewed by the hospital's (1) inpatient paediatric pain service, this service did not (and still does not) provide an outpatient chronic paediatric pain service.
- 6.45 Child A's GP and the CCNT questioned the on-going amount of Fentanyl that was being prescribed and requested a consultant review of the on-going need for such a large amount of pain relief. This was later discussed in a paediatric gastroenterology psychosocial meeting and it was acknowledged that a referral to a chronic pain team may be needed. However, no referral or other action was taken.
- 6.46 The GPs were under the impression that Child A was being assessed by a chronic pain team and so continued prescribing the opiates, downgrading their own concerns. However, these were false reassurances as Child A was never seen by

the pain team. The GPs were influenced by the hierarchy of medical professionals and felt bound to prescribe a medication prescribed by a specialist.

6.47 The need for a dedicated chronic pain team to be involved should have been identified at the time Child A was discharged home on regular opiates. There is no evidence this was considered at this time.

6.48 Child A's parents reported that '*They felt psychologically dependent on the Fentanyl as it meant they could do something about the pain. As a parent you don't question you just do it*'. They reported they had no idea that the Fentanyl was making Child A's pain worse. They did not appreciate that Child A's wider symptoms of sickness, headaches, abdominal pain could have been caused by the Fentanyl. They were concerned that they were not told that children are no longer discharged home on Fentanyl.

**6.49 Finding 3: The lack of provision of a local chronic pain team contributed to the inadequate monitoring and supervision of Child A's long-term medication.**

#### **6.50 What Needs to be Done Differently**

- Children should not be discharged home on long term opioids except for palliative care.
- There is a need for long term pain management pathway for children following discharge from hospital.

**Recommendation 12:** The City & Hackney CCG should review the availability and accessibility of chronic pain services for children in order that effective care pathways can be developed and implemented.

**Recommendation 13:** The CCG / NHSE should seek assurance that General Practice and community pharmacists have protected learning time regarding the prescribing and dispensing of opioids for children.

**Recommendation 14:** The City & Hackney CCG should review competency framework and support for GP safeguarding leads and impact of GP local incentive scheme to ensure that GP safeguarding leads are confident in their roles as set out in Working Together 2018 and by the Royal College of General Practitioners.

## 6.51 Non- Attendance, Cancelled & Postponed Appointments

*Article 19 UNCRC: all children have the right to protection from all forms of violence, abuse, neglect and mistreatment by their parents or anyone else who looks after them.*

- 6.52 The SCR identified that Child A was not taken to a significant number of healthcare appointments because these were either cancelled by the hospital (1,2,3) or mother or postponed by mother on the basis that Child A or herself were not well enough to attend.
- 6.53 Child A is a vulnerable disabled child who relied on their parents to get them to appointments or accept home appointments. Cancelling these appointments arguably made Child A more vulnerable. Whilst practitioners had concerns about the number of appointments not being attended, there is little evidence that these were escalated through supervision or that local policy was followed.
- 6.54 Given there was no lead professional for the family, different professional groups were not fully aware of the extent of the cancellation or postponing of appointments. The lack of shared healthcare records compounded this matter.
- 6.55 It was not until 2017 that a multi-disciplinary meeting convened by health services identified the extent to which medical appointments had been cancelled or postponed by Child A's mother. There is no evidence that professionals working with Child A considered that this might constitute neglect. There also appears to have been little consideration given to the impact of mother's health issues and her ability to facilitate Child A's attendance at all the appointments.

6.56 The fact that mother cancelled, or postponed appointments, as opposed to Child A 'not being brought', might have meant that health practitioners viewed these circumstances as being subtly different. This is likely to have influenced their view of potential risk and may account for the lack of proactive action in response to these events. Regardless of the reasons, the consequences can be the same and involved professionals should have been more robust in their challenge of this issue.

**6.57 Finding 4: There were weaknesses in the processes to monitor the repeated postponed or parental cancellation of Child A's appointments.**

**6.58 What Needs to be Done Differently**

- All children who are not brought to appointments should be followed up, for whatever reason, initially through the family and family GP to ensure there are no safeguarding concerns.
- All health providers must ensure there is an up to date 'Was Not Brought' policy and that all paediatric staff are familiar with the associated guidance.

**Recommendation 15:** The CHSCP should request safeguarding partners and relevant agencies review their systems and policies regarding children not brought for appointments to ensure these extend to include children not brought to appointments through cancellation or postponement.

**Recommendation 16:** Multi-agency and single agency safeguarding training should include the potential safeguarding impact on children not being brought for health appointments.

## 6.59 Professional Coordination

*Article 24 UNCRC: every child has the right to the enjoyment of the highest attainable standard of health.*

- 6.60 The family had an increasing number of health professionals working with them from the time of Child A's birth. This was due to Child A's prematurity, presentation of symptoms and a shifting diagnosis. Child A was referred to and seen by consultants at three hospitals and in the community by the neonatal nurse, health visitor, community children's nursing team, portage, physiotherapy, occupational therapy, wheelchair services and dietetics. The serious case review identified that over the course of 11 years, Child A was seen by over 150 health care professionals.
- 6.61 The Francis Inquiry (2013) identified failings over co-ordination of care and made recommendations to address this, identifying that GP's have a responsibility for monitoring delivery of standards and quality.
- 6.62 The review identifies that no one professional had oversight of the services and investigations being undertaken. Child A was being seen by a significant number of professionals without evidence of a clinical pathway to follow. This led to a lack of co-ordination by any professional and mother understandably felt she had no choice but to take on this role herself. Child A's mother felt she was co-ordinating care from the outset, telling the review that there were no discharge planning meetings.
- 6.63 Practitioners spoke of mother being very strong minded and determined in her relationship with them to the extent that professionals did not feel or were not able to challenge her actions or decisions. This was particularly evident when mother continually cancelled appointments and meetings. When Child A was in hospital (1) and on patient-controlled analgesia (PCA), there were also concerns that mother was managing the PCA herself.

- 6.64 During the review, practitioners spoke of father's professional background and mother's reported nurse training, influencing their perceived expectations of the parents. Practitioners believed that the parents would have known what services were available and would have been able to ask for these if required. The consequence was that Child A did not receive all the care they were entitled to.
- 6.65 When interviewed as part of this review, Child A's parents said that '*things went seriously wrong when Child A was discharged home on Fentanyl*'. They reported a '*complete lack of co-ordination and lack of medical management with no support*'.
- 6.66 The role of the GP is a primary record holder for medical notes and the provision of community medical services (alongside the Child Health record held by parents). It is clearly useful for children with complex care needs and their parents to know their GPs and to have good access to primary care. Given the quantity of medication prescribed, it would have been good practice for the GPs to review Child A in line with GMC guidance<sup>30</sup>. During one consultation, the GP held a long discussion with mother about Fentanyl use, although there were no actions that the GP proposed to take.
- 6.67 The consultation was viewed as positive with the GP writing '*the situation is difficult but well managed by mother*'. The GPs appeared to accept that mother was managing well without consideration for professional oversight. With children who have complex medical needs, it is not unusual for the majority of their medical care to occur within secondary care settings. However, it is especially noticeable that primary care had minimal interaction with Child A and this is unusual.
- 6.68 Child A's mother was put in a powerful position as being the main communicator between primary and secondary care, as Child A was often seen by a consultant outside clinic times and she had access to his mobile number.

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<sup>30</sup> <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/prescribing-and-managing-medicines-and-devices/reviewing-medicines>



- 6.69 It was identified through the review that this was not unusual, and that the consultant had given his mobile number to other families. This resulted in clinic letters not being written and the wider healthcare team (both in the hospital (1) and in the community) being unaware of what was being discussed and what the plan was.
- 6.70 This was further exacerbated by telephone calls between the consultant and mother which were not recorded. This unusual system carried with it the possibility of misunderstanding / manipulation. Information was not being shared from clinician to clinician, but between one clinician and the parent and then from the parent to other involved clinicians.
- 6.71 Child A was being seen by a number of different consultants and specialist consultants at three different hospitals which, in the absence of a lead professional, prevented a comprehensive overview of Child A's medical conditions and treatment.
- 6.72 It appears that no single health care provider had a full picture of Child A's medical needs, treatment or of the family functioning. There was a disproportionate reliance being placed on mother's perception of the diagnoses and treatments of other professionals in the network. This impacted on decision making about Child A's health and care needs.
- 6.73 Finding 5: The absence of a lead professional to co-ordinate and communicate the input of different professionals supporting Child A risked diagnosis and treatment being based on inadequate information. This inappropriately left Child A's parents with the responsibility to pass communications and information between practitioners.**
- 6.74 What Needs To Be Done Differently**
- There is a need for a lead professional for children who have complex needs and who are over-medicalised (perplexing presentations).

- Over-medicalised children who are receiving healthcare services from a wide range of professionals should be allocated a professional healthcare worker who can be impartial and have a complete overview and understanding of the presenting healthcare needs and medical conditions to take the lead
- There should be Team around the Child meetings for all children with complex perplexing presentations.

**Recommendation 17:** The CHSCP should seek assurance that partners have agreed processes for agreeing a lead professional, a care co-ordinator and a system of multi-agency team around the child meetings for children who are being over-medicalised.

## 6.75 Education and Home Schooling

*Article 28: of the UNCRC states that every child has the right to an education.*

- 6.76 Child A was appropriately referred for a Statement of Education under the 2002 SEN framework. What followed was a complex decision-making process involving the local authority's education services and Child A's parents in an attempt to ensure Child A was placed in the right educational environment.
- 6.77 The education services attempted to assess and determine the right establishment which would provide the right level of educational support and at the same time have the ability to support Child A's complex healthcare needs. Child A's parents told the review they felt that Child A's medical needs and pain management meant their child could not cope in mainstream school and Child A initially went to a school for children with physical disabilities and additional sensory needs.
- 6.78 Child A's poor health meant that attendance at school was significantly impacted due, in the main, to authorised absences requested by mother. The parents

decided they would like home tutoring, although the rationale for this decision and other possible options weren't further explored by education professionals.

6.79 However, the pattern of Child A's health inhibiting education continued. On occasions, when being home tutored, Child A's mother would ask for the sessions to end reporting that Child A was too unwell to continue.

6.80 The change in provision of education from school to home tutoring occurred at the same time as the 2014 SEND reforms which culminated in a reorganisation of the educational services in the area. Child A ultimately got 'lost' in the system and no one received any reviews about educational progress for a number of years. Child A was formally recorded as still being a pupil at their former school, and as a consequence the school was assumed to be responsible for Child A's annual reviews. These did not take place for four years.

6.81 Education services did not monitor Child A's education provision in any sense during this time. Child A continued to only receive five hours educational input per week until summer 2017. This change followed the raising of wider concerns about Child A's welfare, after which there was an annual review and home tuition provision increased to 12.5 hours a week.

6.82 Education staff spoken to in this SCR acknowledged that it was an extremely difficult period at the time and that systems have subsequently improved. Review processes have been strengthened to ensure all children have timely reviews. There is also reported to be much improved working with health professionals and the designated medical officer in order that children with complex medical needs can be discussed.

**6.83 Finding 6: There was an insufficient response in meeting Child A's educational needs.**

## 6.84 What Needs to be Done Differently

- The review process for all children on an EHCP should ensure that all assessments and reviews take place on time.
- All EHCP plan reviews should have impact statements to demonstrate that children are progressing.
- There is a need for increased medical involvement by the designated Medical Officer for those children on an EHCP with complex perplexing presentations.
- Children should be involved at all stages of the development of the EHCP and their review.
- Education providers must ensure that children have the space and freedom to learn outside the family unit.

**Recommendation 18:** The CHSCP should reassure itself that the quality and monitoring of alternative education provision is sufficient.

**Recommendation 19:** The CHSCP should reassure itself that processes for the assessment, provision and review of education for children with SEND are sufficiently robust.

## 6.85 The Escalation of Safeguarding Concerns

*Article 19 of the UNCRC states that governments must do all they can to ensure that children are protected from all forms of violence, abuse, neglect and bad treatment by their parents or anyone else who looks after them, including health care workers.*

6.86 Escalation of concerns for a child is paramount to support decision making and ensuring a child is safe. It is central to established safeguarding practice and procedure. The review identified many examples when practitioners should have

escalated their safeguarding concerns, including when mother declined services (Health Visiting and Portage) or cancelled or postponed appointments (referral to the Pain Team). It was not until Child A was ten years old that a referral was made to Children's Social Care. A lack of escalation was similarly highlighted in the RCPCH report 2018, commenting that there was '*uncritical challenge*' by other team members.

6.87 When exploring the reasons why concerns for Child A weren't escalated further, the review identified a range of reasons:

### **6.88 Professional Hierarchy**

- Whilst the RCPCH review 2018 identifies there is a more open culture now, junior professionals can be reluctant to escalate their concerns about senior colleagues. Overall, a theme was heard from a number of practitioners about their inability to challenge the expertise of hospital specialists. This appears to be a widespread cultural phenomenon.

### **6.89 Family Dynamics – Impact on the Recognition of Need & Risk**

- Some professionals believed that because of the professional background of the parents, that the family knew what services were available to them and hence, these would not need to be explained. Others spoke of being very conscious of father's professional experience and that this caused a nervousness, inhibiting escalation to Children's Social Care. Some said that because of his background, they found it difficult to believe there could be any child safeguarding concerns.
- Mother was perceived by practitioners as an articulate and assertive woman with firm views and thoughts about her child's health and treatment. Professionals reported that this impacted on their ability to respond to Child A, properly establish views, focus on needs and challenge parental accounts. The impact of parental assertiveness on professionals has been noted in

previous SCRs (Kingston Family A 2015)<sup>31</sup> and in the work of Bernard 2017<sup>32</sup> who identified that '*Some practitioners reported being put under a lot of pressure to respond to the demands of the parents which made it difficult to maintain a child-focus approach*'.

- In many aspects of Child A's care, professionals appear to have avoided 'difficult conversations' with the parents. This may have been influenced by professionals not wanting to 'make matters worse' for the family, particularly given mother's health issues and the clear challenges she was facing both personally and as a parent.

## 6.90 Accessing Supervision

- For some professionals, there was a lack of confidence and understanding about appropriate access to safeguarding supervision. Supervision should have led to escalation of concerns but did not.

## 6.91 Thresholds

- For some professionals, there was a lack of understanding about the threshold for referring to Children's Social Care.

## 6.92 Complaints

- For some professionals, there was a concern about complaints being made. Some did not feel they could '*raise their head above the parapet*' and refer to Children's Social Care for fear of being parental complaint.

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<sup>31</sup> Serious Case Review Family A; Kingston LSCB 2015  
<https://kingstonandrichmondsafeguardingchildrenpartnership.org.uk/media/upload/fck/file/SCR/Family%20A%20Serious%20Case%20Review%20Report%20November%202015.pdf>

<sup>32</sup> An Exploration of How Social Workers Engage Neglectful Parents from Affluent Backgrounds in the Child Protection System; Bernard 2017 <https://www.gold.ac.uk/media/documents-by-section/departments/social-therapeutic-and-comms-studies/Report---Neglect-in-Affluent-Families-1-December-2017.pdf>

### **6.93 Social Media**

- There was a concern raised by some professionals regarding the use of social media by some parents, who have used this to attack individual practitioners.

### **6.94 Finding 7: Practitioners insufficiently challenged and failed to escalate their concerns about Child A.**

### **6.95 What Needs to be Done Differently**

- Practitioners should not delay in making a referral to Children's Social Care through potential false assumptions about a parent's knowledge or experience of services or for fear of reprisal through social media.
- Parental behaviours and needs, such as assertiveness and their health issues, should not divert practitioners from their focus on the needs of a child and any required action based on those needs.
- NHS Trusts should ensure when addressing a complaint against staff, that the potential inappropriate use of the process by parents and or carers to avoid the detection of abuse and neglect is recognised.
- All professionals working in paediatric services must have access to and utilise safeguarding supervision.
- Children's Social Care and health partners to recognise each other's roles and expectations in respect of decision making.
- Any practitioner who has safeguarding concerns about a child should, at an early stage, consult their Safeguarding Lead, e.g. Named GP, Named Doctors and Designated Professionals.
- Considerable experience, practice wisdom and knowledge of neglect are essential in relation to working with highly resistant parents who challenge professional's decision-making.
- Different health trusts safeguarding teams would benefit from working collaboratively when children known to both their services are escalated to them. This would result in a more effective risk assessment, a more effective

safeguarding plan for the child and clearer communication with parents and professionals on what needs to change.

**Recommendation 20:** The CHSCP should review its escalation policy to ensure it incorporates supporting professionals being able to challenge colleagues within and outside their own organisation.

**Recommendation 21:** The CHSCP should include in its multi-agency training programme the theme of over medicalisation, its management and the importance of escalation in this context.

**Recommendation 22:** The City & Hackney CCG should review and reinforce GP safeguarding training to emphasise the importance of early recognition of a child at risk and escalation to children's social care.

**Recommendation 23:** The City & Hackney CCG should seek assurance that when there are safeguarding concerns and children are under more than one health provider, there are processes to ensure the relevant health safeguarding teams work collaboratively to ensure their safety and there is guidance on how to manage difference of opinions.