Suffolk Safeguarding Partnership

Serious Case Review

Young Person Mary

Overview Report

October 2020

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Contents

1. Introduction

1.1 This is the report of a Serious Case Review into the life of Mary and her brother John. John died unexpectedly on the 27th November 2010 aged 9. The cause of his death was cardiac arrest following an asthma attack. Mary died on the 19th February 2018 aged 13, just 7 years after John, also following a severe asthma attack. It was established that the attack was not anaphylactic in origin (despite Mary being highly sensitive to a number of allergens) and likely to be due to a sudden and acute asthma attack on top of chronic under treated asthma.[1] There has been to date, no similar incidence of two asthma related deaths in the same family known to the Independent Expert who reviewed both cases[2].

1.2 Whilst Mary (and indeed her brother) were not considered to be at high immediate risk of harm, there were regular and ongoing concerns about underlying ongoing neglectful care at home, difficulties with the appropriate management of her condition and the presence of animals and cigarette smoke. In addition, the family dynamics were complicated, there had been an acrimonious split and ongoing and severe parental disputes, and difficulties involving new relationships. Both parents were known to smoke. An independent review was commissioned by the NHS in Autumn 2018 which reached a number of conclusions. These conclusions supported the case to undertake a Serious Case Review[3].

1.3 A number of services had contact (and at times direct involvement) with both children so it is particularly important to reflect on how they worked together in Mary and her brother's best interests and to safeguard their health and welfare.

2. Summary of learning

2.1 The review found that too many people tried too hard, too tenaciously, and too patiently to engage Mary's mother in meeting Mary's health needs. Intermittent social care engagement was unhelpful in understanding the core issues. This was compounded by the degree of sympathy from a wide range of professionals for Mary's mother in relation to the death of John, which diverted attention from focussing on Mary's own needs. It also found that safeguarding concerns focussed on neglect and practical care, and not on the core issue of her health care. Professionals in the main, made too many allowances for her mother and were insufficiently challenging.

2.2 Social care did not recognise the overall impact of poor asthma management or the impact of her family's adversarial behaviours on Mary's life, focussing on addressing physical conditions and neglect. They did not utilise previous assessments to inform the next assessment or period of involvement. Health care agencies did not communicate or review the long history of missed appointments or recognise that if aggregated they would meet the threshold for triggering safeguarding processes. Education staff took too much for granted and did not consider whether the fact that Mary's asthma improved when she was not living with her mother was significant information that should be discussed with colleague professionals in social care and the NHS.

2.3 Mary's story was not sought, explored, or considered. Her voice was largely missing from the records.

2.4 The findings did not identify that any of the issues identified were an immediate causal factor in or directly linked to her death. She died from an acute episode of asthma, possibly linked to long term poor management of the condition.

2.5 This review has identified four key areas of learning:

The approach to long term conditions.

The way in which agencies and organisations recognise, respond to and manage long term life-threatening but common conditions such as asthma needs to be improved.

Assertive Practice

Highly articulate, plausible, and manipulative parents require confident and assertive practice, and a focus on the core issues. Professionals need to act in the child's best interests and consider what their

[1] Conclusion by Independent Expert Clinicians based on the records 27.06.2018

[2] Report by Dr Isles and Dr Pearce (undated)

[3] ibid

life (in all aspects) is like. Professionals must challenge parental assertions, views, and behaviours from a child centred viewpoint. Talking to, and listening to children's own views, experiences, and wishes is central to assertive practice. Parental views should not dominate or override evidence-based concerns.

The interagency system

Agencies need to coordinate or communicate sufficiently well to fully understand what the issues are. They need to share historic knowledge of the family with each other. Core concerns for one agency need to be shared with, explained, and understood by others, and a common set of understandings developed that inform current and future practice.

Professional recognition of safeguarding concerns

Parental minimisation of professional concerns or failures by parents to comply with advice and management requirements in relation to health care issues should be treated as a safeguarding matter, which triggers child protection processes, as necessary. Superficial or short-term compliance with expectations set by professionals is not good enough and sustainable change in practice by parents should be the goal.

2.6 Many things were also done well during Mary's life. Her death was unexpected, her health improving at the time and was not a direct consequence of any professional limitations or failures. It is clear some of the learning from John's life and death was applied especially by NHS services. When the professionals involved met to consider, reflect on and debate what happened some good practice was identified as were some areas of practice which could be improved on.

3. The Approach Used

3.1. The Terms of Reference[4] for the review were agreed in June 2019 and the full version can be found in appendix one of this report.

3.2. Following Mary's death, a formal referral was made to the Suffolk Safeguarding Children Board (SSCB). The Panel found that the case met the criteria in Working Together to Safeguard Children 2015. The Independent Chair agreed to proceed with a Serious Case Review (SCR) based on the following factors:

1) The concerns around chronic neglect of children in the family home.
2) The findings in Dr Iles' report identified signs of significant neglect
3) Partners were seriously concerned about the parent's ability to accept and implement advice regarding the health of their children in order to meet their complex health needs.
4) There are concerns around how the different agencies working with the family effectively worked together to address the above concerns.

3.3. The subjects of the SCR are John and Mary. The scope of the review was from January 2010 to February 2018. This is a long timeframe and covers the period of both siblings' deaths. Each agency prepared an agency timeline of significant events (chronology) together with an analysis of relevant context, issues or events. Information about the action taken in response to the analysis was included as appropriate. These reports were completed by managers who had no operational responsibility for the case. Report writers were asked to use their judgment and focus on the key, relevant points during this period in order to produce focused reports when compiling and analysing chronologies of their involvement with the children and their family members.

3.4. The review had access to an Independent Report commissioned by the NHS and a composite analysis report compiled by the Ipswich and East Suffolk and West Suffolk Clinical Commissioning Group Designated Nurse.

3.5. The review was also informed by the debate at a multi-agency learning event held with front line practitioners and managers in each agency who were involved with John and Mary. The event explored what had happened over John and Mary's life, what went well, what did not go so well and what can be learnt from it.

[4] Terms of Reference Vs 2 Agreed June 2019

3.6. Mary's mother, Alice and brother, Peter and her father, David and his partner, Joan were seen before the review began, and had the opportunity to recount their experiences, express their views and contribute anything to the review process they felt was relevant

3.7. The Review was undertaken by an Independent Author, Jane Held, who has substantial experience of Children's Services, and has led a number of Serious Case Reviews (SCR's). She was supported by a multi-agency Review Team who oversaw the analysis and debated the key learning identified and its implications for improving practice.

3.8. The key questions explored by the Review are:

- Was there enough professional curiosity and challenge regarding the family home and behaviours and the impact this had on the children's wellbeing?
- Were there effective interventions and referrals to ensure the children were safe?
- Was information shared effectively across agencies, particularly Education, Health and Children's Services?
- Did partners allow the complexities of the family arrangements to distract from the safety of the children?
- Did professionals effectively support the parents in their ability to understand the needs of the children?

3.9. As the review progressed the question of whether the multi-agency system fully understood the significance of asthma as a potentially fatal chronic illness and how important effective management and compliance are in treating it was also fully explored.

3.10. The full structure and terms of reference for the SCR are attached as Appendix 1.

4. Key Messages

4.1. The death of one child in a family from asthma, which is a treatable condition If properly managed is a tragic event. The death of two in the same family is so rare no other cases have been identified and it must have been devastating for all concerned. It inevitably gives rise to questions about whether something was not learnt or applied from John's death in order to prevent Mary's. The review has established that this was not the case.

4.2. It is clear when seen retrospectively that the quality of parenting Mary received from her mother, whilst loving, was at best haphazard and was frequently unacceptably poor. Protective factors within the household mitigated the impact of this, but Mary became self-sufficient and responsible for her own care at an early age. The acrimonious relationships between her mother and father, her mother's own emotional challenges and the complex family dynamics often diverted attention from Mary's asthma.

4.3. It is clear that Mary was largely responsible for managing her own medication. Given her age this is understandable, but records indicate she may have relied on medication that gave short term relief of symptoms. She does not appear to have been well enough informed or supervised to ensure she was consistently using the other more important medication provided to prevent rather than relieve symptoms.

4.4. The reasons why this was the case are not wholly clear. Asthma is a condition which requires a high degree of structure and compliance with proven therapies and treatments. Her immediate maternal family members were at times, inconsistent in their compliance and particularly resistant to following the professional advice given about the use of the preventative medication prescribed for her.

4.5. Mary had been well for a significant period before the crisis. Her death was sudden, unexpected, and distressing. Although no one specific allergen or irritant triggered the crisis, her home environment was not ideal for her, with a significant number of pets, and a family who smoked but there was no direct causal link identified between her death and her home environment. The trigger for her death was not identified and she died from an acute exacerbation of her asthma.

4.6. The review confirmed that at certain periods in her life, her care was not as it should be for a child with asthma (particularly when her older brother had already died as a result of an asthma attack). She was not brought to a significant number of clinic and GP appointments, her living conditions were at times poor and consistently included specific allergens (smoke and pets) despite advice to remove them and the quality of her parenting was inconsistent in nature, although she had strong bonds with her parents and older brother.

4.7. This review has also identified that some partners across Suffolk did learn from John's death. Asthma is a condition which requires a high degree of structure and compliance with proven therapies and treatments. They applied that learning and practice changed as a result.

4.8. There was also a period of good, persistent and assertive social work practice with Mary and her family, as well as constant ongoing efforts by all partners to keep the family engaged and involved despite, at times, no clear role for individual agencies. There was an awareness of thresholds for intervention and when the risk of physical neglect to Mary significantly increased, the right action was taken by social care. Much of the time the issues were rightly not identified as significant enough to take any formal statutory safeguarding action.

4.9. However at times advice could helpfully have been taken by NHS staff from safeguarding advisers, which may have changed practice in terms of addressing the persistent challenges presented by Mary's mother's resistance to a consistent level of attendance at clinics and appointments for Mary.

4.10. It is clear that Mary's death was not a consequence of any poor practice by any service or professional. John's death had led to some changes in practice, which were being applied. There is none the less significant learning from this review about working with children with chronic ill health and complex parental family circumstances, including when there are aspects of neglect and a resistance to accept and apply professional advice.

4.11. The key messages are that:

1) In a family that is complex, dynamic, adversarial and resistant to advice, professionals need to exercise professional curiosity about what life for a child is really like at home, and how well the adults caring for them are supported to manage and apply the advice provided. Talking to a child is insufficient. Active efforts to build a relationship, and really seek to understand their own life experiences is essential if the child's voice is to be heard and acted on.
2) Professionals, especially in the NHS need to be sufficiently curious about what is happening in a family, pro-active in addressing issues before they arise, and assertive about issues that require active proactive intervention. Whilst this may be counter-cultural in a system based on diagnosis and treatment, proactive identification, and management of causes (whether they are social or medical) is essential when It is clear treatment regimens are not being followed.
3) The management of chronic illness in childhood needs multi-agency, whole system information sharing, planning and management and a shared understanding of when parental lifestyle matters become life threatening as well as potentially or actually neglectful. In addition, all professionals need to understand that asthma is a potentially fatal chronic illness and one which requires significant levels of consistent management and oversight, compliance with medication regimes and avoidance of factors which could make the condition worse. Their response to signs that such compliance is missing should be a safeguarding based response.
4) Patterns of behaviour, the chronology of a case, consistent incidents of a particular type, cyclical deterioration in effective parenting, and the historical context all need to be taken into account when evaluating the significance of and risks inherent in a particular situation or area of concern. An assessment or intervention should always take into account these issues when analysing what course of action to take.
5) When involved in cases of serious parental dispute, practitioners, especially in social care, should avoid distancing themselves from the issues to prevent being "drawn into" the arguments. They need instead to actively question what the story is behind the disputes, and what is really going on for the child or children involved, even if it does not appear that there are immediate concerns about the child's welfare or safety.
6) Front line practitioners, particularly in children's social care need to apply the same principles regardless of whether it is a child protection matter, a child in need concern or a Team Around the Child process. In all contacts, assessments and interventions, practitioners need to understand the child's "story", context, and circumstances, evaluate risk, identify strengths and concerns, and then actively drive change to improve the child's life. The process being applied is less relevant than the quality of the practice involved. They need to apply a degree of respectful disbelief, even after any adults involved have experienced significant and traumatic events, as well as responding to that distress sympathetically.

5. John, Mary & their Family

The Family Structure

5.1. Mary's family consisted of a significant number and range of different adult relationships, all of which were, in various ways adversarial and at times difficult. Her father and mother split up. Various other adults formed relationships with Alice and David, Mary's parents, over time. There was ongoing tension between the various adults involved in Mary's life all the way through the period covered by this review. The most significant adults in Mary's life were her mother, father, and older brother.

The home environment

5.2. Both Mary's parents smoked. At her mother's, Mary lived in a household that included a number of pets, the combination and number of which changed regularly over her lifetime. At the point she died there were three dogs, a cat and two caged Sugar Gliders (a type of small possum) in the household. The house was frequently described by professionals as dirty, at times smelly, untidy, unkempt, and unhygienic. Mary's bedroom was at times observed to be unclean and covered in animal hair. Her father's house was clean and well cared for. Following Mary's return to her mother the house was redecorated and remained in better condition for the rest of Mary's life although it was observed to be still messy and unkempt at times.

John and Mary's life

5.3. There is little in the record that gives an indication of what John's life was like at home. The 11 months of the review scope that covers his life deals primarily with a series of asthma attacks, attendance at the Emergency Department of West Suffolk Hospital, unauthorised absences from school (8 in the last year of his life) and erratic attendance at the GP asthma clinic. Records show that John's asthma management and control was "not good" and he had a number of emergency admissions to hospital with acute attacks, meaning his life was significantly affected by his illness.

5.4. At the time of John's death (whilst visiting at his grandmother's house) the police described the home conditions as "bordering on neglectful" and the Grandmother's house as smoke filled. A new puppy had been bought just before John's death. The cause of John's death was acute uncontrolled asthma exacerbated by an inflammation of his heart.

5.5. The records are fuller in relation to Mary. Whilst John was not deemed to have significant allergies, Mary, over time, was diagnosed as allergic to house mites, dust, hay, pollen, rabbits, horses, cat hair, dog hair, and almonds. Recognised triggers in relation to her asthma included cold weather, and colds as well as her allergies. She carried an epi-pen, but her death was not triggered by an allergic reaction.

5.6. At her mother's she had considerable independence for her age. She enjoyed school and achieved well. Her attendance was reasonable with relatively few unauthorised absences. She was helpful, friendly and keen to please at school and looked for adult attention.

5.7. Life at home was not always easy for Mary especially before the period she went to live with her father and his partner. Records from that period show she was often hungry, not always very clean or well dressed, and that she was expected even as a young child to make her own packed lunch[5]. The death of her brother, on her 6th birthday had a significant influence on her life, and at times she became distressed about it. Her views about her mother and father changed over time. When younger she did not want to see her father without Peter, her older brother being with her. At first whilst living with her father she did not want to see her mother, but she then gradually began contact again and decided to stay with her mother as her father's partner was "*not nice to her*"[6].

5.8. After her return home she continued to have a lot of independence but was supported and cared for by her older brother and his partner. She appeared to the school to be reasonably well cared for. She had a lot of friends and enjoyed a range of activities. On the day of her death she had been into Bury St Edmunds shopping with her family and some friends and came home "*happy*"[7].

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[5] Taken from interviews with staff who identified that the food she was bringing was also sometimes inedible.

[6] Direct quote taken from records

[7] Direct quote taken from interview notes

5.9. However, Mary's own voice is largely missing from the records. Her schools provided what appears to be significant emotional support but did not always record this, or consider whether, in the light of her family life and medical conditions, they needed to liaise with other agencies. All her clinic records show the communication was between her parent, or the adult accompanying her to an appointment, rather than, particularly as she got older, directly with her. No one attempted to discuss her asthma directly with her, talk to her about why she was using so much of her reliever medication but so little of the preventer treatment. Nor did they talk to her about what made it better or worse. Her views were sought and listened to in relation to her desire to move to live with her father, and subsequently her move back home, and had a significant influence. However, that influence did not include listening to and talking to her about managing her asthma better

6. The Family Perspective

6.1. The Independent Overview Writer and the LSCB Board Manager met with Mary's mother and older brother and heard from them their experiences of both John and Mary's death. The trauma of these events remains with them. They expressed feelings of being badly treated by professionals when they felt they personally were trying to do their best for the children. They were also clear that, in their view there had been professional overreactions to issues such as the animals in the house. They spent some time talking about how they had been careful to ensure the animals they kept were ones Mary was not allergic to and emphasised that they smoked outside the house not in it.

6.2. It appears from the records and listening to Mary's mother, Alice and brother, Peter, that home life was for much of the time rather more relaxed than in many homes. There were clearly many fun events and occasions and relationships were strong if sometimes fractious. They both agreed that Mary's care had not been good enough after John's death and things slipped as a consequence of the trauma. They were equally very proud of how hard Peter had worked to improve conditions at home and to make sure Mary was properly cared for.

6.3. Peter was angry that the nebuliser they felt worked well for John was not returned after death, so Mary did not have access to it. They did not think the medication prescribed for Mary was suitable. They felt they had worked hard to make sure Mary was compliant with her regime and were confident that she was good at self-managing. They challenged the possibility that she was resorting to her "reliever" inhaler by habit and over-using it. They were very clear that in their view she managed her illness well.

6.4. Their perspective was that Mary's father, David had done everything he could to focus attention on Alice by making false allegations. They were angry about social care supporting David to take Mary home and "out of their lives". Peter was clear Mary wanted to come home, and he was pleased he had facilitated that. They were not sure that a Serious Case Review would help with closure for them. They felt strongly that Mary's death was something they were not responsible for and could not have prevented.

6.5. The Independent Overview Writer and the LSCB Board Manager also met with Mary's father, David and his partner, Joan. They were extremely angry about Mary's death, and the fact that Mary was allowed to go back to live with Alice. They continued to say what they had consistently said over the years about Mary's mother's care being neglectful and that no one had listened to them. They described how carefully they had parented Mary, and monitored her asthma compliance, and education. They reminded the reviewer that Mary's health had improved significantly whilst she was with them (although records show she did have one acute episode whilst still living with them).

6.6. Mary's father clearly loved his daughter and was deeply traumatised by the loss of both children. He was hurt that he was not there and could not help them. Life for Mary at Dad's was obviously much more boundaried, with strong routines and clear expectations about cleanliness, bedtime routines, food and homework etc. It sounded to be very different to her experience at her mum's.

6.7. Neither of them felt Social Care could, in effect, be trusted and they expressed frustration that no one had been identified by the police as responsible for Mary's death. They felt Mary's wish to return home had been because she could get away with things at her mother's that she could not get away with at their house. They also felt that she had been allowed to make her own decision, something that was not in her best interests to be allowed to do.

6.8. Both sets of adults could not talk of the other without considerable acrimony and allegations about their behaviour. This must have been very difficult for Mary. Both sets of adults also consistently expressed their strong views that what happened was not their fault. They all blamed others, including third parties, and understandably wanted someone else to be found to be responsible. The fact that both children died

of “natural causes” made no difference. Neither felt the SCR would establish what had happened and that it was not really going to change anything, although Father expressed the hope that it could help stop something similar from happening again.

7. Key Practice Events during Mary’s Life

January – November 2010

7.1. During this period, the agencies who had contact with John and Mary were primarily the primary school, the GP and West Suffolk Hospital. There are a series of records about Mary’s physical care, (smelly, dirty, tired), practical care (inedible lunch snacks) and concerns her that her mum regularly smelt strongly of alcohol. No referrals were made.

7.2. John had to attend Accident and Emergency early in 2010 with his asthma and had several GP attendances with acute episodes as well as a couple of episodes at school. There were concerns about John’s over-use of the reliever inhaler and concerns he was not making regular use of the preventer inhaler. There were also issues for both children around follow up appointments not being made, and non-attendance at appointments (‘Was not Brought Episodes’.) Mary was taken to the hospital in October for a clinic appointment. Her mother gave the paediatrician inaccurate information about the number of courses of steroids she had been given over the year (1 not as records show, 3)

Comment

Whilst there were concerns at the primary school about the degree of care the children’s mum was giving they were not seen as serious enough to meet the threshold to justify a referral. The GP practice was assiduous in following up requests for appointments. There was no evidence that an asthma management plan was in place for either child and the medical practitioner concerns about over-use of the reliever inhaler were not assertively pursued.

7.3. There continued to be concerns throughout the period of the review about the degree to which Mary’s mother understood the purpose of the preventer inhaler, an over reliance on the reliever inhaler, poor attendance at appointments, lack of follow up, and mother ignoring advice and/or under playing the seriousness of the condition.

Following John’s Death

7.4. John died from a cardiac arrest during an acute asthma attack exacerbated by myocarditis. He was at his maternal grandmother’s house at Mary’s 6th birthday party at the time. Sudden Unexpected Death in Childhood (SUDIC) protocols were immediately applied.

7.5. The initial SUDIC meeting heard from the police that conditions at home were *“bordering on the neglectful”* and the police felt that the conditions need to be addressed for Mary, and her older sister Elizabeth’s unborn baby. The SUDIC chair suggested there might need to be a Child in Need (CIN) referral made in respect of Mary, and a recommendation was made that Mary be reviewed at asthma clinic. The action plan was not clear about who should make that referral.

7.6. The follow up SUDIC meeting discussed the poor physical home conditions, the number and type of pets in the household and the level of cigarette smoke, the impact on Mary’s asthma, Mary’s mother’s non-compliance with treatment and monitoring requirements in relation to Mary’s asthma and the poor condition of the medical apparatus in the house being used by John (nebuliser and inhalers)

Comment

Whilst both SUDIC meetings discussed the degree of concern about Mary’s asthma and the level of poor care and poor compliance in the home neither meeting made a formal referral to Children’s Social Care about these concerns. A referral was made for an Asthma Review. This meant that Children’s Social Care, who did begin an initial assessment of what was happening within the family, were not provided with key information about asthma which would have helped establish exactly what people were worried about and what should be done about it. As a consequence the focus of social care was on the physical neglect issues.

January 2011 – July 2011: Child in Need services

7.7. The initial assessment was triggered following the second SUDIC meeting. It explored the issues drawn to their attention. These were primarily about the home conditions. Family relationships were also explored. Both mother and father's homes were visited. Mary said she did not want to visit her father without her older brother Peter being present. A Child in Need (CIN) meeting was held and a core assessment undertaken. A CIN plan was agreed. The assessment was primarily focussed on the home conditions, and on both parents' ability to care properly for Mary. What was not fully explored was the potential link between the exposure to cigarette smoke, the large number of pets at Mary's house, including a parrot, and Mary's asthma.

7.8. During this period Father's partner Joan's past history was identified as a potential risk and Mother made untested allegations about Father's inconsistency in relation to contact arrangements and his and his partner's alcohol use. Concerns also emerged about the change in Mother's behaviour since she began a new relationship with a female partner. There was work done to repaint and improve the home conditions and school identified that Mary was brighter in herself.

7.9. During this period, the School Nursing Service and Social Worker made two joint visits and worked to engage Mary's mother and brother in considering the best way to manage her asthma. The School Nurse was clear about the impact of pets, smoke etc as well as about the need to manage Mary's asthma proactively. Alice, and her son were concerned that the police had destroyed (as dangerous) the nebuliser John had used, as they felt it should be available to Mary. The School Nurse attempted to clarify the situation. The GP was not asked to prescribe a nebuliser for Mary and it was not deemed to be clinically necessary.

7.10. Mother did not take Mary to three Asthma Clinic appointments nor did she respond to letters requesting she make further appointments. When they did attend Mother said Mary was symptom free and that she had a Paediatric Clinic appointment booked. Mary then had an asthma attack requiring hospital treatment, at which she was also diagnosed with allergic reactions to nuts, grass and dust mites and given an Epi-pen. A further attack a few days later was treated by the Out of Hours Service.

7.11. The case was stepped down to a Team around the Child (TAC) approach after discussion between the Social Worker and Manager about improvements in Mary's home conditions and a Common Assessment Framework Referral was made to trigger this in June 2011. The rationale given was that the concerns were primarily health related.

Comment

There appear to be two key practice issues during this period. The first is the focus during the initial assessment period on the home conditions and possible neglectful care without fully understanding, being informed about or including the relevance to Mary's asthma and the nature of her home life to safeguarding considerations. The second is that as home conditions improved Social Care stepped back. A link was not made between neglectful care, and treatment compliance. A holistic approach was not taken to what was a concern, what was going well, and what should be done despite the multi-agency planning framework in place through the CIN plan.

July 2011 – December 2011: Team around the child

7.12. The TAC and CAF processes began a month after the decision to step the CIN approach down but the transition was not particularly smooth. The Primary School made a CAF referral. Once established the TAC process was clear, and persistent. A short Initial Assessment of David's suitability for Mary to stay overnight with him was completed by Social Care, at his request.

Comment

An initial assessment was begun as part of the support package being offered to the family. It was not completed as David withdrew from involvement. Social care said to David they would reopen it should he request it. At this point the later concerns about his partner's own family history were not known.

7.13. Concerns continued to be expressed by clinicians and NHS staff about how well Mary was managing her asthma given the very high level of Ventolin (Reliever) use that Mary appeared to rely on. At a Clinic

Appointment mother's request for a nebuliser was turned down as it can *"give a false sense of security*"[8]. She was told that the proper administration of Mary's preventative inhaler using the right breathing techniques and an Aerochamber was just as effective.

Comment

> *The discussion about a nebuliser was context specific, and the wider environmental and social issues within this family were not taken into account in terms of achieving good compliance. Consideration was not given as to why the family had such a strong preference for a nebuliser, or to whether they accepted and agreed with the clinical view as to the best treatment. A family where compliance is already an issue may not accept and follow medical advice no matter how clinically sound it is. Extra care needs to be given to how compliance is monitored in these circumstances.*

7.14. The school at this time had child protection and welfare concerns about Mary, linked to the inappropriate and challenging behaviour being exhibited at school by Mary's mother and her new partner, intelligence about the new partner being unkind to Mary, the lack of focus by Mother and her partner on Mary and her needs and care and their focus on the new pregnancy. Mary was looking uncared for, was often smelly, and hungry, and said she had to get her own breakfast and make her own packed lunch. She also had a severe infestation of untreated headlice. When these concerns were raised with Mary's mother, she did not agree that they were issues and withdrew her consent for a TAC Plan and Services.

7.15. The Integrated Team continued to visit and monitor the situation for a number of months despite Mother's withdrawing of consent and the case being closed officially in October 2011. The Lead Professional continued to "hold the case". The Social Work Service also continued to be involved but solely in relation to assessing Mary's father's suitability for overnight stays. Integrated Services staff expressed the opinion that things at home had not improved and that Mary's mother did not appear to understand or accept the seriousness of the issues causing concern. How strongly this was communicated to others is not clear.

7.16. The School Nursing Service was proactive, and communicated regularly with Family Support staff, the School and the GP Surgery to gain an overall picture of how well Mary was. Concerns increased during October and stepping intervention up to Child in Need provision was discussed and seen as necessary. Despite this level of concern and the evidence of neglect as well as of emotional distress a decision was made to fully withdraw and close the case after a discussion about the play therapy Mary was being provided with through the Hospital Bereavement Service.

Comment

> *It is not clear why a referral was not made to Children's Social Care at this point as professionals clearly felt the threshold was reached. It is also not clear why the level of concern about neglect, (emotional, medical and physical) was not taken into account when a decision to close the case was taken. It appears practitioners across the multi-agency system did not have a full picture of Mary's life, the issues she was dealing with, and what role each professional had in relation to safeguarding her. The role of Children's Social Care was also unclear in relation to the family and may have given some professionals false assurance.*

December 2011

7.17. David and Joan moved into a house with a spare bedroom for Mary. This triggered further assessment activity by Children's Social Care given concerns about Joan's past history. Mary confirmed that she wanted to stay overnight with Dad as well as just visit. The Social Worker sought Alice's views about this as part of the assessment but was unable to speak to Alice, so relied on the views expressed by Aileen, her new partner. After further visits to father and to mother, and the preparation of a written agreement with Father, Mother was informed that Social Care were content with overnight stays. The case was closed as the assessment was complete. Mary was able to stay overnight at her father's house.

[8] Taken from records

Comment

This assessment took a long time. The final decision was made after fully evaluating the potential risk to Mary from Joan's past history and weighing up every aspect of Father's ability to meet Mary's health as well as physical and emotional needs. No account was taken of information available from the extensive involvement with Mary and her mother and family members through the TAC team. This limited the overall judgement as to what was in Mary's best interests. The assessment was task and objective focussed and was not sufficiently holistic or focussed on Mary's overall circumstances.

May 2013 – October 2013: new concerns

7.18. Between May and October 2013 new concerns arose. A referral was made by a GP in May 2013 after Father reported concerns that Mother was still administering tablets to Mary after a course of anti-biotics were completed and that Mary (aged 8) was left alone to baby sit the new baby. The GP noted there had been a number of missed appointments at the surgery and hospital in recent months.

7.19. An Initial assessment began and was concluded after a home visit. Mother said Mary was well and had not had to attend her GP, a statement which was not consistent with the GP referral. The Assessment noted the previous involvement was linked to supporting the family after John's death and some concerns about the state of the house but did not refer to the issues about asthma management.

Comment

This was a limited initial assessment. It did not interrogate what was known about Mary's family life or consider the current situation in depth. It focussed primarily on the primary reason for the referral (maladministration of medicine). The family history, and previous concerns were not taken into account. At the time there were two recording systems, one for early help and family support services and one for children's social care. The two systems did not "talk" to each other and could not easily be accessed by professionals from a different service, making it hard to get a complete picture. The concerns in the referral about Mary's mother not keeping appointments were never addressed.

7.20. In August a further referral was received from the GP in relation to a burn to Mary's hand she acquired when she was making a bottle up for the baby. Another Initial Assessment began and there was an unannounced visit to Mary's home but the family was not in. David was seen as part of this assessment. It proved difficult to see Mary's mother although she gave a plausible response to the burn and how she dealt with it when spoken to by phone. After a two month delay in trying to see Mother, permission was sought from Mary's father to interview Mary at school. At this point the school "had no concerns" for Mary who was attending school regularly and was clean and well presented. The GP and School frequently saw Mother's partner Aileen with Mary rather than Alice herself.

7.21. Despite two missed appointments, Mary's lack of attendance at her GP was interpreted as evidence of her being "healthy" rather than as a consequence of lack of care by her mother. The Social Worker involved had clearly read the family history and accepted the recorded reason for the social care involvement after John's death (i.e. for support and because the house was dirty). The case was closed to social care without a further conversation with mother to triangulate information and challenge her assertions.

Comment

This was a missed opportunity to identify exactly what Mary's life was like at this point. A burn caused by an eight year old "filling a baby's bottle" from a kettle should have given rise to a more assertive and curious approach to an Initial Assessment, and (given the history) a more assertive challenge of Mary's mother.

January 2014 – October 2014: Asthma related incidents

7.22. Between January and September 2014 there were several asthma related events, including an ambulance call out and admissions to hospital. There were also a number of referrals to the police in relation to domestic violence incidents between Mum and her ex-partner, Aileen over access to their son Justin. The significance of these was not identified and links to the previous family history not made. Mary was demonstrating distress and emotional upset at times and told the School Nurse at a drop-in that she

was unhappy at home. This was dealt with directly with Mary in school and not communicated to other agencies or professionals.

November 2014: Initial Assessment and Child in Need

7.23. In November 2014 Mary's paternal grandmother made a referral which included the information Mary was unhappy at home, and that her physical care and home environment were both poor. Paternal Grandmother was also concerned Mary's mother did not take Mary to appointments. The response was thorough, the history and context reviewed and the weaknesses in the previous Initial Assessments were identified. Mary's views and father's views were sought, and a Comprehensive Assessment began.

7.24. During the Assessment unsuccessful attempts were made to visit Mary's mother and an incident at school took place where Alice did not respond to a request to collect Mary who was feeling ill. When she ultimately responded and did arrive, she shouted at her daughter. After a home visit, Mary's mother was told clearly and assertively to improve the home environment. The assessment was comprehensive and completed by the end of December 2014. It identified the risks of Mary's asthma and clearly recognised the potentially fatal nature of poor compliance and management, and the weaknesses of Mary's mother's approach to it. A CIN plan was recommended and a meeting planned.

Comment

This was a thorough, well managed, well evidence assessment which identified and focussed on the core issues.

February 2015 – August 2015: moving to live with Father

7.25. The CIN meeting was held. David attended but Alice did not. David demonstrated an insightful, appropriately concerned, and measured response. David when it was suggested as an option, agreed that he should take Mary home to his house from school that evening to live with him, given the level of concern that was identified about home life at her mother's home. The meeting decided to support Dad's decision at the end of the meeting. Children's Social Care wrote a letter indicating their support of Father's decision but making it clear the decision was Father's; that he had parental responsibility so legally was able to do so; and that it was a private matter between both parents. The letter made it clear that it was not a social care response or social work decision. Social Care agreed to remain involved although voluntarily.

Comment

This was a sensible decision by Father, and the meeting's response was pragmatic and sensible. Legally it was defensible. Although the letter was clear, subsequent events indicate that Father and Mother both thought and continue to believe that it was a decision made by Children's Social Care as part of their powers. Social Care's continued involvement in Mary's life was entirely right in the circumstances but was voluntary with no statutory powers. This may not have been well understood.

7.26. Initially Mary settled well with her father, Joan and her half-brother, Mikey. Father behaved appropriately in terms of care and of attention to Mary's own health needs. Joint School Nurse and Social Work visits were positive, and Health Assessments indicated there was a significant improvement in Mary's health as well as a drop in her use of the reliever inhaler. She did have one trip to hospital in this period. Mary told the School Nurse she was happy at Dad's. A decision was made by March to close the case as all the actions identified in the Assessment had been addressed. Father was advised by social care that if Mother wanted to have Mary back, he should seek legal advice rather than ask Social Care to intervene.

7.27. A referral was received in April 2015 (after the case had been closed) from Mary's brother Peter indicating she was at risk of harm at Father's as he had been violent towards Peter and that Mary was unhappy at Father's house. Peter was given advice by the team who took the referral that it was a private law matter and they would not intervene.

7.28. In August 2015 David made a referral to Children's Social Care after Mary had gone to her mother's house for the weekend. She was refusing to return to her father's home. She had said she was unhappy because of Joan's attitude towards her. His concerns were appropriate and well-pitched and had validity. He was advised to make an immediate legal application to resolve the matter. Children's Social Care decided that if there was no order made immediately by the Court, they should undertake a new Statutory Assessment of Mary's care and wellbeing. They had informed Children and Family Court Advisory and

Support Service (CAFCASS) at the time that the matter was a private family matter based on the record about Father's decision to move his daughter, without reference to other concerns. No order was made on David's application to the Family Court so another Comprehensive Assessment began.

Comment

The closure of the case after Mary's move to her father was completed without due consideration of what Mary's life might be like if her Mother wanted her back. There was no contingency planning in the event that Mary returned to her mother's care, without any improvements in the home environment. This approach was system rather than child focussed and did not give due weight to the issues that had caused the original concerns. Nor did it recognise that whilst the dispute was strictly a private family matter the concerns about Mary's life historically, including at the point she moved to her father were sufficient to justify reengagement and a degree of professional concern and curiosity from Social Care.

September/October 2015: Assessment completed

7.29. The Common Assessment was finalised by September 2015. During the Assessment Mary was asked her views but through closed not open questions. The Assessment did not include discussion about or analysis of the impact on Mary of the pets and cigarette smoke at home. The Assessment also did not include significant contributions from the secondary school Mary was attending, or GPs and the Hospital. The School said they noticed no changes in Mary after she went back to Mother. The GP practice had no concerns even though they had been contacted by Mary's father during the Assessment. This was when Father wished to express his concerns about mother and request that the GPs monitored Mary's medication use. Father was not fully involved, or his views sought as part of the assessment.

7.30. The case was closed as the Assessment concluded there was no role for Children's Social Care. No consideration or weight was given to the strong assessment made by a different social worker prior to Mary's move to her father, or to the evident improvement in Mary's health at her father's home. This conclusion was passed to CAFCASS during the Family Law Hearings that Father had initiated when Mary first returned to her mother. A further referral by father to Children's Social Care about the level of Mother's care was also passed directly to CAFCASS.

Comment

This Core Assessment was neither as comprehensive or as robust as the previous one. It did not explore the history of Mary's life or the issues of how managing her medication well was essential for her wellbeing and health. As the Family Court and CAFCASS were involved at the time it is understandable, whilst not helpful, that Children's Social Care wanted to close the case. It is perhaps regrettable that Mary's life was not more carefully considered, and that the issues were erroneously identified as being about the tensions and dynamics between her parents rather than her mother's capacity to care for and protect her.

7.31. CAFCASS' involvement with Mary was in what is known as the "Work to First Hearing" stage of private law proceedings. At this phase CAFCASS has a clear remit to undertake a range of checks designed to provide objective information that identifies any specific risk factors. Telephone interviews are conducted to triangulate information and explore and understand risk and protective factors. They use this to complete the CAFCASS Safeguarding letter which is sent to the courts and usually sent to both parents. At the first hearing the court decides whether it has enough information to make a decision and final order, or whether further information and assessment is needed. In Mary's case the information provided by social care was based solely on the most recent assessment and did not identify any safeguarding concerns. That and the fact that Mary's father did not attend the hearing, and Mary had expressed a wish to stay with her mother meant the court felt they had enough information to conclude the case. Mary remained where she was.

The last period of Mary's life

7.32. From November 2015 to Mary's cardiac arrest, she did not come to the attention of Children's Social Services in any significant way. There appeared to be significant improvements in her home life with Peter and his partner providing a reasonable level of stable and appropriate care.

7.33. In April 2016 her secondary school took Mary away to Lourdes and her health improved over the trip with careful regular monitoring of her medication. The significance of this was not recognised. Overall, over

two years, there was an improvement in her asthma control /use of salbutamol inhalers. This was despite the ongoing pattern of missed appointments and a continued lack of response to GP/Clinic requests. Her asthma was poorly controlled for a short period in late 2016 and Mother was again told about the link between pets, cigarette smoke and uncontrolled asthma and reminded that Mary should not rely on her reliever inhaler.

7.34. Regular inter-adult disputes also continued. Mary seemed resigned to these and told the school after her Father had talked to them about his concerns, that "she was happy at home with Mum and it was just Dad trying to get at mum". Mary had a good relationship with school staff, confided in them, and sought help from them. They did not share any concerns they may have had with external professionals.

7.35. On the 15 February 2018, Mary had a severe asthma attack after her bath. She had been well and gone on a day out with friends. She died after a cardiac arrest. The Post-mortem examination concluded the cause of death being "acute exacerbation of asthma". Of note the trigger for the asthma attack was not identified. The police investigated the ongoing care of Mary with due consideration to the death of her brother John in 2010. Consideration was given to criminal offences of neglect and cruelty, but the case was not progressed as there were no grounds to do so. In fact, the evidence was that life for Mary was improving at the time she died. Her health seemed to have improved with some clinic appointments attended. An assessment by her GP in Oct 2018, although only a brief review, stated Mary appeared to be healthy and happy. The home visit concluded that whilst not ideal the home conditions were suitable and did not meet the threshold for neglect. She had been living there with pets since 2015. The police investigation showed no evidence of a causational link between Mary's care at home and her death following the acute asthma attack on 15th February 2018.

7.36. As Mary died from natural causes there was no inquest.

8. The NHS Review

8.1. It is understood to be extremely rare if not previously unknown for two children in a family to both die as a consequence of severe asthma. An Independent Review commissioned by NHS partners in Autumn 2018 identified a number of concerns about neglectful care in relation to Mary. The same Expert (an Expert in Respiratory Paediatrics) subsequently undertook a review into John's death. The final report was a combined one.

8.2. The Report noted that John had severe uncontrolled asthma that was under recognised by medical care, accepted as normal by his family, who in turn failed to seek appropriate medical advice with regard to the chronicity and persistence of symptoms. With regard to Mary, the number of missed appointments for Asthma Reviews; non-compliance with medication; non-compliance with requests to stop smoking, address basic hygiene requirements, and avoid pets meant Mary was not living in a suitable asthma friendly environment despite Mary's death, which contributed to her severe uncontrolled asthma and subsequent death.

8.3. The report set out the pattern of events relating to Mary's asthma from 2005 to 2018 taken from NHS records. This table provides a powerful summary of the impact on her life of her asthma.

Event	2018	2017	2016	2015	2014	2013	2012	2011	2010	2009	2008	2007	2006	2005
Acute asthma event	1		1	5	6	2	1	5	4	2	3	1	7	0
Acute health care other	0	0	0	0	0	0	0	0	0	3	5	3	3	15
Planned Health Care review	0	2	6	5	5	4	2	5	3	0	0	0	1	2
DNA requested appts	0	6	2	2	3	3	3	6	3	0		1	1	0
additional reminders for he	0	3	2	3	2	3	0	3	1	0				0
Total calls to attend	0	11	10	10	10	10	5	14	7	0	0	1	2	2
Neglectful parental action					2	1								
Injuries	0	0	0	0	0	1	1	1	0	0	1	0	1	0

8.4. It is clear that the NHS made determined efforts to ensure Mary was regularly reviewed and her medication adjusted as necessary. It also notes that it appears Mary relied on her reliever inhaler as her primary form of medication, rather than on regular use of her preventer steroids, and additional medication designed to support long term control of the condition. The Report notes that repeated recommendations were made to Mary's family to improve her living environment by Primary and Secondary Care and School

Nursing. This review concurs with that conclusion. School nursing in particular, played a very important role. Changes however were limited or short lived.

8.5. The author notes there were 5 unexplained injuries and refers to 5 referrals as well as to one formal referral to Social Care which did not reach the threshold for action. No trace of those injuries or referrals can be identified in the NHS or Social Care records and the review is satisfied that this must be a misunderstanding. There are referrals on record especially from the GP. The records show good evidence of discussions between Clinicians, Social Workers, Family Support staff, and School staff about the issues and concerns raised as they arose.

8.6. The Report supported and informed a decision to undertake a Serious Case Review. The decision was based on four factors:

1) Concerns in relation to chronic neglect of children in the family home.
2) The findings of the Independent Experts' report in relation to the causes and treatment of both children's asthma.
3) Concerns about the children's mother's ability to accept, implement and comply with advice in relation to her children's complex health needs.
4) Concerns about how effectively different agencies working with the family worked together to address the above concerns.

8.7. The review posed 5 key questions which the following analysis addresses.

1) Was there enough professional curiosity and challenge regarding the family home and parental behaviour and the impact this had on the children's wellbeing?
2) Were there effective interventions and referrals to ensure the children were safe?
3) Was information shared effectively across Agencies, particularly between Health, Education and Social Care?
4) Did partners allow the complexity of the family arrangement to distract them from the safety of the children?
5) Did professionals effectively support the parents in their ability to meet the needs of the children?

8.8. A further question this review also explored was whether professionals recognise when there is a need to take action for children with chronic illness or chronic conditions which, if not managed well, constitute a risk to a child's health, welfare and development.

9. The Learning Event

9.1. The learning event considered a draft of this report and debated on a multi-agency basis what went well, and what did not go so well, and what learning can be gained from this.

9.2. In summary the participants, many of whom had been closely involved with Mary and her family felt that what went well was:

- Constant tenacious pro-active reminders to Alice about missed appointments throughout the whole of John and Mary's lives, proactive as well as reactive and in various forms. This meant Mary got to appointments after 3 or 4 reminders each time *but that reduced alertness and prevented escalation of concerns. It raises questions about when "enough is enough" regardless of short-term changes*
- The very clear concerns identified at the first SUDIC meeting after John's death *but the concerns about asthma management were not communicated to social care leaving them focusing just on part of the problem*
- The strong assessment by a social worker after concerns had resulted in referrals (prior to Mary's move to live with her father) which included a recognition of the risks attached to poor management of Mary's asthma
- Good school support at both schools, with oversight of her medication. The secondary school felt Mary was independent and good at self-management, *but no questions were raised about Mary's reliance on her reliever medication rather than her preventer*.
- Very good levels of information exchange between the GP Practice and Community paediatrician, better than usual standards *but the communication was about facts and maintaining attendance – not questioning the wider context or the impact of such a long-term pattern of concerns*
- School nursing was used well by Mary at her secondary school, and she got good emotional support as she used the drop-in service well *but the school nursing service dealt with the issues*

within their service, did not communicate with other agencies and may not have focussed enough on asthma management

- Alice was verbally articulate, appeared open and willing to listen and engage in attended meetings and appeared cooperative, reflective and traumatised by John's death and keen to promote her daughter's wellbeing and frequently improved her level of care after meetings *but this diverted attention from her resistance to accepting advice, and reduced concerns, and diverted professionals from seeing the longer term picture and patterns of care*
- Mary lived within a family unit where she appeared to have good relationships, especially with her older brother who provided much of the consistency, care and oversight of her asthma management over her latter years at home, *but this diverted attention from her mother's role as a parent*

9.3. Overall, much of the work done by professionals was, if seen in isolation, well within reasonable and good standards. In discussion, professionals recognised that the good practice frequently meant the wider context, history and focus was diluted or diverted, as evidenced by the comments in italics.

9.4. What did not go so well was largely an extension of what went "well enough" and practitioners recognised this.

- As things for Mary were just about good enough much of the time and improved every time concerns became more significance the case was never viewed as meeting a threshold for statutory safeguarding interventions. Multi-agency safeguarding discussions did not take place often enough when things deteriorated. Safeguarding is an issue even if statutory thresholds for child protection action are not met, but the approach to the situation did not recognise this.
- The question of "when is enough, enough" was not explored within organisations or in multi-agency discussions.
- Referrals did not generate statutory action at times as insufficient attention was being paid to the context, the history or wider story. The importance of recognising patterns of behaviour rather than a focus on incidents was not understood well enough
- Information exchange is not the same as good communication. The latter is more nuanced, questioning, collaborative and reflective, and seeks to explore why something is "as it is", but most practice is process driven, fact based, and progressive in nature. This results in limited understanding of what is happening, and why. After sharing information professionals need to ask themselves and each other "what does this mean for ……."
- In addition, not all relevant information was shared across the multi-agency system, with conversations about different aspects of Mary's life taking place in different professional contexts, rather than being shared appropriately with others. Information held by the Multi-Agency Safeguarding Hub (MASH) was not accessible to other agencies despite its importance and relevance.
- There was limited use of chronologies and no integrated chronology was available. Whilst multi-agency integrated chronologies are hard to create within current recording systems, they are invaluable in understanding the history of a child's life
- Where information was shared and plans made, insufficient attention or weight was given to follow through on decisions, the sustainability of a plan, and the need for alternative options should plans not succeed
- The majority of professionals tried really hard to engage Alice, and keep her engaged and on board, but were often insufficiently assertive about what was expected and the consequences if it did not happen. Alice was not sufficiently challenged, and the fact that when she was challenged, she would just walk away was not recognised as a risk factor or concern. Her ongoing grief about John's death meant professionals tended to be more sympathetic in their interactions with her than they might have been in other circumstances
- Professionals need to feel confident about when and how they speak directly to the child or children, rather than via parents or carers
- SUDIC meetings need to include all the agencies involved with a child, especially their school

11. Analysis

11.1. Mary died as the result of an asthma attack just over 7 years after her brother John died in similar circumstances. She lived in a family with complicated family dynamics, inter-personal acrimony, strong views and attitudes and at times neglectful circumstances. Mary lived mainly in a house with several pets at any one time, and both parents smoked which were both identified as potential triggers for her asthma along with her allergies. Mary's mother was resistant to expressions of professional concern about home life and able to assertively justify why pets and smoke were not an issue for Mary.

11.2. Much of the time, Mary's life was not as good as it should have been given her chronic health condition.

11.3. There were 4 key points where practice could have been better. None of them were directly linked to or causal in Mary's death, but if practice had been different Mary's life experiences may have been better. These were:

1) When the SUDIC meeting after John's death did not communicate fully about the concerns that had been identified about medicine management and compliance
2) Limited social work assessments and responses to significant concerns about Mary's care in 2013
3) The approach taken to Mary's move to her father, the limited understanding of social care's power and role as a consequence and the absence of ongoing oversight, or planning by social care in relation to the possibility of a potential move back to her mother.
4) The insistence that the move back to her mother was a private matter, and the affect that had on CAFCASS's understanding of the circumstances, as the proceedings did not progress to a full assessment.

11.4. Towards the last years of her life Mary's situation did improve, and she received better consistency of care from her brother's presence in the household. The same issues however were present at the point she died as had been when her brother died in terms of medication management, pets, smoking and other allergens. John's death did not trigger any lifestyle changes for her maternal family, although her overall living conditions did improve. The question is what can be learnt from this for future practice in similar circumstances?

Good Practice

11.5. The review has demonstrated that there was some good and effective practice at times which made a difference to Mary's health and welfare. There were some extraordinarily persistent NHS efforts to rectify the poor control and over-use of reliever inhalers that was identified as a concern. Coupled with this was really good partnership working during the period of concern after John's death when the neglect issue became significant. There were 2 joint visits to Alice and Mary by the school nurse and social worker to reinforce what was expected. All through Mary's life there was alert and appropriate school monitoring of her health and her welfare and her school provided her with a lot of support.

11.6. In a way this persistence, whilst commendable, obscured the underlying issue, i.e. being able to recognise and identify when parental life styles or resistance to change and advice becomes serious, potentially life threatening and not merely an irritation, worrying, or neglectful.

11.7. After Mary's mother withdrew her consent to the Team around the Child service, the integrated team persisted in monitoring what was happening. This was an indication of the degree of concern they felt. Their willingness to overlook the issue of parental consent and cooperation in order to ensure Mary was being looked after well enough was commendable.

11.8. The quality of recording overall was thorough across all agencies, and decisions are recorded. There were also some skilled and appropriate social work interventions and an excellent comprehensive assessment prior to Mary being subject to child in need plans and interventions. There was also good investment in and provision of bereavement support to Mary and an appropriate risk assessment of Dad's partner (although this took too long as it was low priority for over worked practitioners).

Professional curiosity and challenge

11.9. Throughout the period of the review there was a real absence of interrogative and professionally curious exploration of what was really going on at home for Mary. Seen with hindsight it is clear that Alice was skilled at avoidant behaviour, and in finding ways to minimise professional scrutiny. At least twice social workers could not "get hold of" Alice and relied on (in one instance) third party information and on seeing Mary herself outside the home. Surprisingly, there was no proper parenting assessment of Alice's capacity although the factors that should have indicated it would be helpful were all present.

11.10. Mary's family were very well known in the village. As is often the case in rural areas, what their lifestyle was like was accepted as just "how it is" at a local level (school, GP practice etc). The fact that Alice had a "big" personality, was outgoing and often abrupt, as well as her tendency to drink more than was helpful was known but was not seen as part "of the picture" or communicated well to other professionals.

11.11. It may also be because of the trauma for the family caused by John's death meant additional allowances were made for Alice's own stress and distress and she was given more leeway by professionals who cared about her and her family's circumstances. This distress was and still is real and Alice did, as she said, fall apart at first. She accepted she neglected Mary during that period.

11.12. The level of neglect never fell to that level again, and home life was reasonable after Mary returned to live with Alice, her brother, Peter, and his partner. However, professionals did not identify or explore the significance of Peter and his partner's role in keeping the house clean, tidy and good enough, and the degree of parenting they provided for Mary. In the latter few years of the review period it appears that Peter was the unrecognised protective factor in the household

11.13. It is striking with hindsight the degree to which Alice and her household persisted throughout Mary's life in justifying why it was ok to have pets, insisting that the reliever inhalers and nebulisers were better forms of treatment, and arguing that they only smoked outside when the evidence was none of this was the case. This strong belief that they knew best remains striking, especially given they had experienced one asthma related death already. Professionally it would be expected that a parent who had lost one child through asthma would be over compliant, overprotective, and over concerned to remove all risks. In the face of that persistent denial the degree of assertive concern from professionals was insufficient and there was limited escalation.

11.14. There was assertive, proper, and continued pursuit of Alice's failure to attend clinics, reviews and appointments for Mary but the staff never fully explored, questioned or got to the bottom of how much Alice understood, and whether she did not bother to follow or accept what she needed to do or whether she did not in fact understand enough to recognise why she needed to comply.

11.15. Whether social work professionals really grasped the importance of these issues and how "normal neglect" was not the real issue is not clear. Whether Alice's approach, attitude and lifestyle was neglectful, and deliberate, or just a completely laid back attitude to managing Mary's condition was not explored. Multi-agency discussions could have helped those non-clinicians involved recognise this better if the meetings had "stepped back" from a focus on the achievement of tasks and expectations to an overview of what was happening.

11.16. At no time did professionals from any agency clearly set out their expectation that "you must do this or else x y or z will happen" so there were no consequences for Alice in terms of professional expectations. Alice was able to change sufficiently to reduce the anxiety expressed about Mary but because professionals then backed off she did not need to maintain any changes.

11.17. There was only sporadic consideration of Mary's wishes and feelings. Records show she was asked a lot about her views, wishes or feelings. No one had an in-depth established relationship with Mary except key school nursing staff at her secondary school. She got a good level of support at her secondary school and took her concerns to them. This helped to support her, as did her relationship with her brother, but did not fully address the issues that affected her health and wellbeing.

11.18. As Mary got older, the GPs continued to communicate via Alice with Mary present, rather than see Mary herself and speak to her directly. Mary was managing her own treatment for several years and a direct conversation with her would have been proper as well as potentially very effective in generating a change in her own self-care.

11.19. It is also questionable as to whether Mary should have been expected to take responsibility for where she lived quite so straightforwardly. She was clearly caught between both parents, and in a household where the other party was always at fault, she must have frequently felt the need to keep both parents happy. Her move to live with her Dad was not her decision, but her decision to return home to mother

appears to have been hers. Professionals did not question whether it was actually her decision to make, not to mention whether it was the right decision.

11.20. Overall there was not enough professional curiosity and challenge. The tendency was to take quite a narrow focus on presenting issues and concerns, rather than seek to answer the fundamental question about Mary's mother's parenting capacity and ability. People also did not ask whether she could actually stop smoking, stop having pets and create/keep a clean allergen free environment, and put her daughter's needs first, or explore what they should do if she could not.

Information sharing and good communication

11.21. Whilst NHS professionals worked hard together, they focussed fairly narrowly on the medical concerns and did not take into account enough the wider context of Mary's life. Whilst at times over the period covered by the review, the family mostly had contact just with school and NHS professionals this was not always the case. Social Care were involved sporadically dependent on circumstances.

11.22. It is hard to identify for most of the time where or when sufficiently coherent arguments as to why social care should be involved were communicated to Social Care, or the Team around the Child. On balance from the records it appears no one felt the threshold for more formal Statutory Interventions was met at any point. No one looked back over history to draw up a picture of the issues "over time". Had they done so, the graphic impact, for example, of the number of "calls to attend" made because a review or appointment had been missed would have been identified

11.23. NHS and Social Care staff when communicating with each other did not always show a good understanding of the importance of context, family history, professional curiosity and information sharing when making referrals or discussing concerns. It is important not to focus on a single presenting concern if possible. It is also important to explain "why" something is important to a colleague with a different professional background.

11.24. The importance of the issue of compliance, the need to focus on preventative medication and not rely on relievers, the need to keep a clean non-smoky and pet free environment etc were not always well enough communicated to non-NHS professionals. This meant the issues were underplayed. The team around Mary, and social care staff tended to focus on practical evidence of neglectful care, emotional need, and family dynamics. It appears that professionals found it hard to effectively support the parents with their ability to understand the needs of their children and put them first.

11.25. This case, like many others without significant incidents that lead to statutory action required good understanding of the story over time, and of what had changed, what had not, and why not. That information was not aggregated or explored sufficiently except for one very good comprehensive assessment. Had practitioners in receipt of subsequent referrals accessed that assessment they may have drawn other conclusions about whether to intervene or not.

11.26. The level of communication and information sharing whilst the Family Law proceedings were underway had a direct impact on the specialist CAFCASS assessment for the court. When CAFCASS contacted social care, to establish whether there were concerns, it was at a point where the most recent records held were that life at home with her mother was going well enough. The history of concerns and the core issues about her health care were not shared with CAFCASS.

11.27. In short lots of information was exchanged, but was not "shared, interrogated or its importance properly understood. Professionals took different perspectives from the same facts. Each agency had their piece of jigsaw and perspective but the exchange between professionals about each other's view was missing much of the time, as was the confidence needed for one set of professionals to be able to say to others, "we do not really understand what that means or why it is important". Multi-agency work requires staff to be alert to their own "professional cultures, languages and knowledge base" and to be ready to "translate" this to other professionals. This is particularly important when complex ill health or chronic medical conditions are involved.

Interventions and referrals

11.28. The expectations of professionals varied over time. For example, in 2010 the school were very worried about how neglected Mary was, but the expectations on the school regarding referrals were very different to how they are now in 2019, so they did not feel it needed to be reported. However, the level of worry, and the continued pattern of the same concerns arising over and over should perhaps have been examined more critically and evaluated over time, rather than incident by incident.

11.29. Overall, there were periods of good and helpful single and multi-agency interventions, which generated short term change. There was some strong practice in 2015/16 but this was followed by some much weaker practice. Interventions tended to be reactive and were short lived. Each new set of interventions involved different personnel, and did not take into account the family history, long term patterns of behaviours, issues and concerns.

11.30. There were 6 assessments of the family and Mary's life undertaken by Social Care, each one by a different social worker. One was extremely good, but the rest were less so, were limited in their scope, and in the analysis and evaluation of the issues. Statutory child protection interventions were never justified as thresholds were not met, and the dynamics of balancing a child's rights to a private family live alongside public responsibilities for protecting children's health and welfare affected professional perspectives, at times to Mary's detriment..

11.31. This "new case, clean slate" approach meant valuable insights and understanding was missed or lost. A loss of narrative through faulty or insufficiently in-depth communication transfer meant that in many instances the original cause for concern was not the focus of the assessment/intervention that followed.

11.32. It is clear that much of the concern (and anxiety) about the issues of Mary's care and home environment and its impact on her life was "held" within the NHS system and accepted as worrying but not sufficient to share or refer. Social workers did not really understand asthma, which was largely seen as a treatable childhood complaint rather than a potentially fatal chronic illness. Whilst the threshold for a statutory safeguarding intervention was not met, NHS professionals needed to share their concerns, worries and the clinical evidence of non-compliance with each other and with social care because of the impact on Mary's welfare. Instead they kept on repeating the efforts to pursue Alice when she did not bring Mary to appointments, to reiterate the importance of compliance and to express concern about the home environment.

11.33. There were no trigger incidents to raise the threshold level of intervention, break the narrative, and give rise to escalation to a more serious level of intervention. The pattern of underlying concerns with a cyclical process of growing concerns, attempts through various interventions to address them, a calm period and then growing concerns was missed. Those NHS staff with a longer history of involvement did not communicate well to others the history or pattern of concerns, focussing on the current issues in each instance.

11.34. Having good arrangements for supervision and oversight of a case, and for taking a "helicopter" view of what is happening is often necessary with families such as Mary's, where the issues fall a little below acceptable levels of care, are constant and ongoing without much change, and which improve slightly for short periods after being challenged. The absence of concerns or incidents that immediately justify a referral can obscure the cumulative evidence that escalation is necessary. Without help to stand back and question whether overall what is happening is good enough over the longer period of time, staff can otherwise just keep on trying.

11.35. The way social care was involved in the decisions made about Mary's place of residence at a child in need meeting, was unhelpful, in that both parents saw the decision as a social work one. This was not the case but neither parent fully understood the legality of what was happening. This created problems when Mary then moved back to her mother. With subsequent referrals social care staff were wary of getting involved in what they saw as private family disputes, having lost sight of the original reasons for their service's earlier involvement. This diverted them from exploring the story behind referrals, from accepting the concerns expressed by David, and from challenging Alice.

11.36. The review has also established that whilst the first half of Mary's life after John's death was overall managed reasonably well it was less coherent after her return to her mother's home. The rational made for case closures or step down to another level of intervention was not always convincing or thought through. In addition, case planning tended to be sequential, by agreeing a plan of action, without alternative action plans being agreed in advance in case the first plan does not work. An example was the support given to David to decide that Mary should live with him, without thinking through and agreeing

what should happen if Mary changes her mind. Referring David to the legal system, whilst the right technical response, was not a supportive or safeguarding focussed approach.

Family complexity

11.37. Another issue was the constant, continuous and still current level of allegations and counter allegations between all the adults involved. The allocation of blame, and no acceptance of responsibility for what was happening by either of Mary's parents had the effect of continuously diverting the attention of professionals away from Mary, what her life was like and from the key issues that needed to be addressed at home.

11.38. This was a complex family situation and was at times extremely adversarial. Alice had a very challenging relationship with her ex-husband, and later in Mary's life, with her ex-partner. Arguments about who was right, wrong and or at fault were commonplace. This was difficult for professionals, as every adult attempted to co-opt them to their view of what was happening and who was at fault. This was not unusual for social services professionals but the fact that this was part of interactions with the family added to the difficulty of assertive challenge and of making well informed decisions.

12. Conclusions and Recommendations

12.1. John and Mary's deaths were not predicted and were both unexpected. It is not clear whether they would have been prevented even if the issue of their home environment, pets, smoking, proper medication management, and regular oversight by clinicians had been addressed. Both had unstable and poorly controlled asthma and strong compliance with appropriate treatment would have gone a long way towards controlling their condition and minimising the risks of serious attacks.

12.2. Lots of committed hard work was put into meeting Mary's health care needs well. There was some good practice on a single and multi-agency basis. The Primary School were vigilant and persistent in raising their concerns in the children's younger years. They knew and managed the children's mother well, despite what in hindsight appears to be disguised compliance.

12.3. Across all agencies with one exception, there was no one professional who was sufficiently or assertively curious about what was really going on for Mary, what life was like for her, and what needed to happen to improve it. There was a limited focus on Mary's own needs, views, feelings and wishes. Too much weight was placed on what appeared to be plausible rational reasons for specific issues and Alice, who was articulate and assertive, as well as avoidant, was not sufficiently or strongly challenged. Genuine concerns expressed by David were misinterpreted as being adversarial and blaming adult behaviour. Efforts were not made to explore the concerns properly.

12.4. The level of apparent neglect as measured by the physical conditions in the house was not sufficient enough of itself to trigger Child Protection concerns. The history and cumulative patterns of incidents, behaviours and issues were not well enough examined, interrogated or at times even looked at those points when concerns arose. Assessments and interventions were based on narrow thinking, were episodic, disconnected, and issue focussed but properly completed. Cumulative evidence was not valued, and the wider context rarely considered. Processes took precedence over systemic and systematic collaborative enquiry and curiosity, and risk was not well identified or evaluated in relation to Mary's health.

12.5. That said, practice was not ineffective, just narrow in scope and focus when reviewed with hindsight. If things had been different, it is still unlikely that Mary would have been subject to significant safeguarding interventions It is clear that when Mary died there were very few concerns about her care or family life and the question remains whether in fact had she not died, would more assertive or statutory action have been taken to improve her circumstances. It is unlikely given the circumstances and her age.

Recommendations:

12.6. It is recommended that the learning from this review is distributed widely to multi-agency professionals in easy to access and key point formats reinforcing the points about how to improve practice standards and the 4 themes (and key messages) from this review about professional curiosity, assertive practice and challenging parents who are displaying disguised compliance and/or resistance to expectations and advice and:

The approach to long term conditions

1) That all health recordings evidence that every missed appointment matters holistically and that previous information has been utilised to help form the next actions to be taken/steps in providing appropriate healthcare.
2) That the NHS partners in Suffolk work together to develop a new protocol and pathway for managing non-compliance when children have asthma That the public health team develop an awareness raising campaign in relation to the risks associated with asthma
3) That short "light bite" sessions are provided for the multi-agency workforce providing information about forms of neglect relating to long term, chronic, or potentially harmful health conditions, and the impact of failing to manage such conditions within a safeguarding context

Assertive Practice

4) That protocols for responding to parental disputes when there is a history of concerns are developed to avoid the "private law" default position that can arise
5) That supervisors focus on (and audit) the degree of assertive practice evidenced by practitioners in a case and ensure staff are supported, skilled up, trained and challenged in terms of their practice with challenging, avoidant, engaging, dominant, emotionally volatile or plausible parents and carers
6) That young people assist the partnership to develop a tool to use with practitioners in professions with less face to face contact with children and young people. This tool should be designed to assist them to talk to, listen to and "hear" the views and voice of children and ensure they are central in their consideration regardless of the circumstances

The interagency system:

7) That safeguarding partners in Suffolk consider how to develop the use of chronologies across all professions and explore any opportunities there may be to develop a shared integrated chronology process
8) That Social Care examines the implications for common assessment, single assessment and comprehensive assessment processes and introduces better approaches to utilising contextual and historical information in assessing cases
9) That the MASH always requests contextual, historical, and repeat behaviours information when discussing referrals – moving from an incident focussed to a context focussed approach to assessing the risk of harm,
10) That the MASH develops ways to ensure multi-agency information is properly distributed and accessible to other agencies when decisions have been made
11) That the NHS consider how best to improve communication between separate NHS specialisms and services and move from information exchange-based practice to communication, reflection, and discussion-based practice

Professional recognition of safeguarding concerns:

12) That a short desk top aide memoir is provided to all multi-agency frontline staff about searching for, recognising and analysing patterns and repeat behaviours when evaluating how well children are being safeguarded and their welfare promoted

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