THE CHILD
SAFEGUARDING
PRACTICE REVIEW PANEL

Out of routine: A review of sudden unexpected death in infancy (SUDI) in families where the children are considered at risk of significant harm

Final report

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Foreword

The sudden and unexpected death of an infant is one of the most devastating tragedies that could happen to any family. In spite of substantial reductions in the incidence of sudden unexpected death in infancy (SUDI) in the 1990s, at least 300 infants die suddenly and unexpectedly each year in England and Wales.[1]

Alongside the overall reduction in incidence, however, there has been a steady shift towards these tragedies happening predominantly in families from deprived socio-economic backgrounds.[2] Increasingly, these deaths occur in families whose circumstances put them at risk, not just of SUDI, but of a host of other adverse outcomes. Many of the recognised risk factors for SUDI overlap with those for child abuse and neglect. And this is reflected in the experience of the national Child Safeguarding Practice Review Panel. Of the 568 serious incidents notified to the Panel between June 2018 and August 2019, 40 involved infants who had died suddenly and unexpectedly, making this one of the largest groups of children notified.

Sadly, most of these deaths are preventable. The risk factors for SUDI are well recognised, and the steps parents can take to reduce the risk have formed part of the clear, consistent and evidence-based safer sleep messages for years. In spite of this, it is apparent that while the safer sleep messages may be rigorously delivered by health professionals, many of those families who are most at risk are either unwilling or unable to receive or act on those lessons for a multitude of reasons.

It seems clear to us, as a Panel, that something needs to change in the way we work with these most vulnerable families if we are to prevent more infants' lives being lost through avoidable SUDI. And to bring about more effective working, we need to have a better understanding of the circumstances in which these babies are dying, how and why their parents are making choices about their infants' care and sleeping arrangements, and how practitioners are seeking to engage and work with families whose children are at risk.

We commissioned this, our second national thematic review, to explore these areas, drawing on a combination of fieldwork, roundtable discussions and a review of the published literature.

The review has identified a number of issues that have helped inform the development of a 'prevent and protect' practice model. We believe this model, if embedded in practice, has the potential to improve the way we work with families with children at risk, specifically to reduce the risks of SUDI, and beyond that, to address a much wider range of risks to their children's health, safety and development. SUDI prevention has all the hallmarks of other

1 NHS Digital (2019). *Child Death Reviews: year ending 31 March 2019.* https://digital.nhs.uk/data-and-information/publications/statistical/child-death-reviews/2019/content

2 P. S. Blair, P. Sidebotham, P. J. Berry, M. Evans, P. J. Fleming (2006). Major epidemiological changes in sudden infant death syndrome: a 20-year population-based study in the UK. *Lancet* 367: 314–19.

safeguarding work and should be understood as such. It is not something that can be left solely within the remit of public health officials, or relegated to the handing out of a health promotion leaflet. Rather, it needs to be embedded within respectful and authoritative relationship-based safeguarding practice. Our hope is that the lessons from this review will be carefully considered by safeguarding partners and by all practitioners working with children and families.

We are extremely grateful to our two reviewers, John Harris and Geoff Debelle, for the tireless work they put into the field visits and case reviews, and for pulling together the learning arising from that work. We are also grateful to the research team, led from the University of Bristol, who carried out the thorough and comprehensive literature review. And finally, thank you to the Panel secretariat for all their work behind the scenes to enable the review to take place and come to completion.

Peter Sidebotham, Sarah Elliott, Susan Tranter

On behalf of the National Child Safeguarding Practice Review Panel

A note on terminology

We were very aware, in writing and editing this report, of the dangers inherent in our use of language, and in particular of labelling children, parents and families in ways that are potentially demeaning and disempowering. The focus of our review has been on families with children who are considered to be at risk of significant harm through abuse or neglect. Our use of the term 'families with children at risk' is a shorthand for this. In using this terminology we recognise that all families contain a complex nuance of resilience, vulnerability and risk, strengths and weaknesses, agency and limitations.

The term sudden unexpected death in infancy (SUDI) is a descriptive term, used at the point of presentation of any infant whose death was not anticipated (see glossary). We have chosen to use this term throughout, rather than the narrower term sudden infant death syndrome (SIDS), recognising that SUDI includes both deaths for which an explanation (medical or external) is ultimately found and those that remain unexplained. Many of the risks, particularly situational and circumstantial risks, are similar regardless of the underlying cause.

Executive summary

Introduction

This review of sudden unexpected death in infancy (SUDI) in families where children are considered at risk of significant harm is the second national review commissioned by the Child Safeguarding Practice Review Panel (the Panel). Infants dying suddenly and unexpectedly represent one of the largest groups of cases notified to the Panel, with 40 notifications between June 2018 and August 2019. While these represent only a proportion of all SUDI, they occur in families who are particularly vulnerable and each one is a devastating loss for the family.

Almost all of these tragic incidents involve parents co-sleeping in unsafe sleep environments with infants, often when the parents had consumed alcohol or drugs. In addition, there were wider safeguarding concerns – often involving cumulative neglect, domestic violence, parental mental health concerns and substance misuse.

The major risk factors for SUDI are well known and the advice on reducing the risks is evidence-based and well established. In spite of this, it was apparent from the cases notified to the Panel that this advice, for whatever reason, is not clearly received or not acted on by some of those families most at risk. It is also clear that, for this group of families, the risks to their children extend beyond the direct risks of abuse or neglect to include wider risks to their health, development and wellbeing.

Within that context, this national review set out to answer the following question:

In families with children considered to be at high risk of significant harm through child abuse or neglect, how can professionals best support the parents to ensure that safer sleep advice can be heard and embedded in parenting practice so as to reduce the risks of SUDI?

The review concluded that:

- A better understanding of parental perspectives by all professionals enables local areas to adopt a more flexible and responsive partnership with parents, develop supportive yet challenging relationships that facilitate more effective safer sleep conversations, and co-produce appropriate information and support for parents and carers to aid their decision-making about the sleep environment.
- There need to be better links between the work in local areas to reduce the risk of SUDI and wider strategies for responding to neglect, issues related to social and economic deprivation, domestic violence, parental mental health concerns and substance misuse. This work needs to be embedded in multi-agency working and not just seen as the responsibility of health professionals.
- The use of behavioural insights and models of behaviour change should be investigated to explore whether these can

support interventions to promote safer sleeping, specifically with this group of families with children at risk of significant harm. Approaches such as motivational interviewing hold out promise, particularly when combined with other strategies for family support and risk reduction. Such an approach could include the use of marketing and social media to influence behaviour change and could be linked to ongoing national work to provide consistent and evidence-based safer sleep messages as part of good infant care and safety.

Method

The review examined 14 incidents of SUDI from 12 local areas that were representative of the 40 SUDI cases reported to the Panel between June 2018 and August 2019.

This was a qualitative study, based on interviews with practitioners and families, underpinned by factual details from each case. The key findings combine evidence from casework visits with insights from wider research in relation to SUDI and its incidence in families where children are considered at risk of significant harm.

There were four parts to the review:

- fieldwork visits in 12 local areas
- discussions with key professionals and experts in respect of SUDI
- a review of the research literature
- analysis of national child death review data 2018/19

Key findings

Families in adverse circumstances

A range of pre-disposing risk factors were identified, which were in keeping with the well-recognised risk factors associated with SUDI. Issues such as smoking in pregnancy were evident alongside social and environmental factors (such as deprivation and overcrowding) that, in combination, are known to increase the risk of SUDI. Co-sleeping was a feature in 38 of the 40 cases. Parental alcohol and drug use were common, as were issues related to parental mental ill-health. These are families that are typically living within a context of recognised background risks and for whom particular situational risks and disruptions to their normal routines mean that they are unable to engage effectively with safer sleeping advice. These findings point towards the need for a flexible and tailored approach to prevention with this group of families, which recognises and is responsive to the reality of people's lives.

Local partnership working

The fieldwork for this review identified some examples of thoughtful, evidence-informed practice, but also wide variations and local inconsistencies in practice. At their best, local arrangements for promoting safer sleeping involved a range of professionals as part of

a relationship-based programme of support that was embedded in wider initiatives to promote infant safety, health and wellbeing. The best programmes are flexible and able to respond to situational risks and out-of-routine circumstances. However, such programmes were patchy in their application, and there were concerns that approaches to preventive work were not sufficiently attuned to the needs of the high-risk population and that resource and time constraints meant practitioners were unable to engage effectively with families where there are additional needs.

Developing a practice model for prevention of SUDI

The findings from this review suggest the need for local working that recognises a continuum of risk of SUDI, with support and interventions that are differentiated and graded to reflect the needs of: all families; families with additional needs; and families whose children are at risk of significant harm. In light of this, we are proposing a 'prevent and protect' practice model with four key components:

- robust commissioning to promote safer sleeping within a local strategy for improving child health outcomes
- multi-agency action to address pre-disposing risks of SUDI for all families, with targeted support for families with identified additional needs
- differentiated and responsive multi-agency practice with families to promote safer sleeping in the context of safeguarding concerns and other situational risks
- underpinning systems and processes with relevant policies, procedures and practice tools that support effective multi-agency practice across the continuum of risk of SUDI.

Conclusion and recommendations

Drawing on the findings from this review, it is clear that families with children at risk of significant harm through child abuse or neglect also face a range of wider risks stemming from their background contexts and circumstances. Situational risks and out-of-routine circumstances act together to increase the risk of SUDI and may mean that families find it difficult or impossible to engage with standard safer sleep messages.

To engage effectively with these families, local areas need to move beyond a framework that sees SUDI risk reduction in isolation from other risks and as solely the responsibility of a narrow range of health professionals. We believe that practitioners in all agencies who are working with families with children at risk need to develop a clearer evidence-informed understanding of parental decision-making in relation to the sleep environment and how this might be changed. Such understanding, backed up by a flexible, relationship-based approach to working, could improve the impact of safer sleep advice on all families, and particularly those with children considered to be at risk.

In light of this, we are encouraging local safeguarding partners to adopt a practice model that encompasses reducing the risk of SUDI within wider strategies for promoting infant health, safety and wellbeing. The report offers a framework for local safeguarding

partners, with questions they can and should be addressing now in relation to the knowledge, understanding and skills of their workforce – in particular, practitioners' understanding of the views of parents about safer sleeping, local multi-agency systems and processes for risk assessment and management, managing workforce capacity, and quality assurance.

In addition, three national recommendations aim to provide effective support for professionals working with families with children at risk.

Recommendation 1

We recommend that the Child Safeguarding Practice Review Panel and the Department for Education work with the Department for Health and Social Care, NHS England and the National Child Mortality Database to explore how data collected through child death reviews can be cross-checked against those collected through serious incident notifications. The aim is to ensure consistency and rigour in both systems, and to explore how national learning from both systems can be most effectively disseminated and acted on at local and national levels.

Recommendation 2

We recommend that, as part of its refresh of the high impact areas in the Healthy Child Programme and the specification for health visiting, Public Health England considers how the learning from this review could be embedded within the transition to parenthood and early weeks. In particular, to consider how targeted multi-modal interventions that provide a safe infant sleep space with comprehensive face-to-face safe sleep education can be embedded in wider whole family initiatives to promote infant safety, health and wellbeing; and to consider how the implementation of these elements of the Healthy Child Programme can be expanded to involve practitioners from all agencies working with families with children at risk.

Recommendation 3

We recommend that the Department of Health and Social Care works with key stakeholders to develop shared tools and processes to support front-line professionals from all agencies in working with families with children at risk to promote safer sleeping as part of wider initiatives around infant safety, health and wellbeing. These tools and processes are intended to supplement the current evidence-based safer sleeping advice to assist local areas in implementing effective preventive work. They could draw on the prevent and protect practice model to enable a flexible and responsive approach, and where appropriate, incorporate relevant and validated risk assessment tools.

Finally, we identify two areas where further research is needed to establish a stronger evidence base in relation to working with families with children at risk specifically to reduce the risk of SUDI.

Research focus 1

There is a need for practice-based research within this country to establish the efficacy of different interventions to reduce the risk of SUDI within families whose children are at risk. The literature review concludes that 'studies should use controlled observations taken from the same population and preferably as a randomised control trial. Where this is not possible, robust evaluations that use objective measures should be conducted'.[3]

Research focus 2

There is a need for further research into the use of behavioural insights and models of behaviour change, working with parents whose children are at risk to develop and deliver effective safer sleep messages and approaches. The use of such models should be thoroughly and carefully evaluated.

3 A. Pease, J. Garstang, C. Ellis, D. Watson, P. S. Blair, P. J. Fleming (2020). Systematic literature review report for the National Child Safeguarding Practice Review into the sudden unexpected death of infants (SUDI) in families where the children are considered to be at risk of significant harm. https://research-information.bris.ac.uk/en/publications/systematic-literature-review-report-for-the-national-child-safegu

Introduction

1. The review question

1.1. This review of sudden unexpected death in infancy (SUDI) in families where children are considered at risk of significant harm is the second national review commissioned by the Child Safeguarding Practice Review Panel (the Panel). Further details about the Panel, its remit and its membership can be found on GOV.UK.[4]

1.2. Between June 2018 and August 2019, the Panel received 568 serious safeguarding incident notifications for children who had died or suffered serious harm. Of those, 40 (7%) related to incidents of SUDI, representing one of the largest groups of cases notified to the Panel. Almost all of these cases involved parents co-sleeping with their infants in unsafe sleep environments, including those where the parents had consumed alcohol or drugs. In addition, there were wider safeguarding concerns, often involving cumulative neglect, domestic violence, parental mental health concerns and substance misuse. While these babies' deaths were not directly caused by abuse or neglect, there are often concerns that the level of parental care may have been a contributory factor that put the babies at increased risk of harm.

1.3. Currently there are between 300 and 400 cases of SUDI per year in England and Wales.[5] Only a minority of these end up being notified as serious safeguarding incidents. The 40 cases notified to the Panel are therefore not representative of the overall population of families experiencing SUDI. National advice on reducing the risk of SUDI has been clear and consistent over many years and is based on current best evidence. All pregnant women and new parents should be given information on safer sleeping, both verbally and in written format. What seems clear from the cases notified to the Panel is that while there is no evidence that this advice is not given routinely, it is not, for whatever reason, clearly received or acted on by some of those families most at risk. It is also clear that for this group of families, the risks to their children extend beyond the direct risks of abuse or neglect to include wider risks to their health, development and wellbeing.

1.4. Within that context, the Panel identified this group of families as a focus for this national review, the review question being:

In families with children considered to be at high risk of significant harm through child abuse or neglect, how can professionals best support the parents to ensure that safer sleep advice can be heard and embedded in parenting practice so as to reduce the risks of SUDI?

4 https://www.gov.uk/government/organisations/child-safeguarding-practice-review-panel

5 NHS Digital (2019). Child Death Reviews: year ending 31 March 2019. https://digital.nhs.uk/data-and-information/publications/statistical/child-death-reviews/2019/content

1.5. The review particularly focused on the following key questions:

- What can we learn from these cases about the ways in which safer sleep advice is currently delivered to and received by families with children at risk?
- How can professionals engage more effectively with families with children at risk to enable safer sleep advice to be taken on board and embedded into parenting practice?
- Is delivery of the universal advice to pregnant women and parents sufficiently risk-sensitive to address the particular hazards detailed above?
- Is any further refinement required in the way safer sleeping advice is delivered to families with children at risk?

1.6. A separate, structured literature review[6] investigated the published research evidence, specifically addressing three areas of the literature:

- interventions for improving the uptake of safer sleep advice in families with children considered to be at risk of SUDI
- interventions to improve engagement with support services
- improving our understanding of the parental decision-making processes for the infant sleep environment in families with children considered to be at risk of SUDI

6 A. Pease, J. Garstang, C. Ellis, D. Watson, P. S. Blair, P. J. Fleming (2020). Systematic literature review report for the National Child Safeguarding Practice Review into the sudden unexpected death of infants (SUDI) in families where the children are considered to be at risk of significant harm. https://research-information.bris.ac.uk/en/publications/systematic-literature-review-report-for-the-national-child-safegu

2. Methods

Fieldwork

2.1. Two expert reviewers from the national pool of reviewers undertook a desktop analysis of the 40 incidents of SUDI reported to the Panel. These 40 cases came from 29 different local authorities in eight of the nine English regions. The serious incident notifications, rapid reviews and, where available, completed serious case reviews of these 40 cases were scrutinised to determine the extent to which any recognised risk factors contributed to the child's death, the nature and delivery of any safer sleep messages, and any insights into how these messages were or were not received and acted on.

2.2. From the 40 notified incidents, the reviewers identified a sample of 14 cases in 12 localities that were representative of the range of circumstances in which SUDI occurred and which covered different aspects of safeguarding risk. The cases all involved infants under 12 months old who had died suddenly and unexpectedly, and the majority (12) were cases where the child or family had previously been identified as being at high risk of significant harm. The full inclusion criteria are listed in Appendix A.

2.3. Fieldwork visits were carried out to each of the 12 localities. During the fieldwork visits the reviewers heard from the local partner agencies about their overall approach to promoting safer sleeping and reducing the risk of SUDI, including any learning from recent case reviews. The reviewers held an extended focus group meeting with professionals involved with the case. Where feasible and appropriate the reviewers spoke to the parents or met a parent focus group. To set the case visit in context, the reviewers also considered a range of background documents provided in advance by the Safeguarding Partners, Child Death Overview Panel (CDOP), and the Health and Wellbeing Board. Details of the specification for the fieldwork visits are provided in Appendix B.

Discussions with key professionals and experts in respect of SUDI

2.4. Roundtable events were held with key stakeholders, including professionals with significant experience in this field and with safeguarding partners from the fieldwork areas. The purpose of these meetings was to test emerging findings from the fieldwork and explore how localities and national organisations are responding to the challenges. Participants were presented with findings emerging from the fieldwork and were asked to reflect on them to consider whether the findings rang true with their experience, any particular points they wished to bring to the attention of the reviewers and Panel, and any examples of practice initiatives they were aware of. The stakeholders involved in these discussions are listed in Appendix C.

Review of the research literature

2.5. The Panel commissioned an academic team, led by the University of Bristol, to conduct a literature review focused on work to reduce the risk of SUDI in families with children recognised to be at high risk of significant harm. The purpose of this review was to seek to understand findings from published research and test these against the findings from fieldwork.

2.6. The literature review followed standard approaches for a systematic review and was registered with PROSPERO, the international prospective register of systematic reviews. Full details of the literature review methods can be found at Appendix D. The full report of the literature review is published separately on the University of Bristol research portal. The key findings pertinent to this national review are included in the relevant sections of this report.

National data on child death reviews and SUDI

2.7. The reviewers examined national data on death registrations held by the Office for National Statistics (ONS) and those held by NHS Digital for child death reviews completed by CDOPs in 2018/19.[7] These data provided a context for understanding the cases included in the review and triangulating these findings with the wider picture of SUDI in England.

Terminology

2.8. The fieldwork visits highlighted the importance of consistent working definitions in relation to SUDI to inform the work of partner agencies. As far as possible, we have tried to be consistent in the terminology used and to work with agreed definitions. A glossary of terms and abbreviations is included in Appendix E.

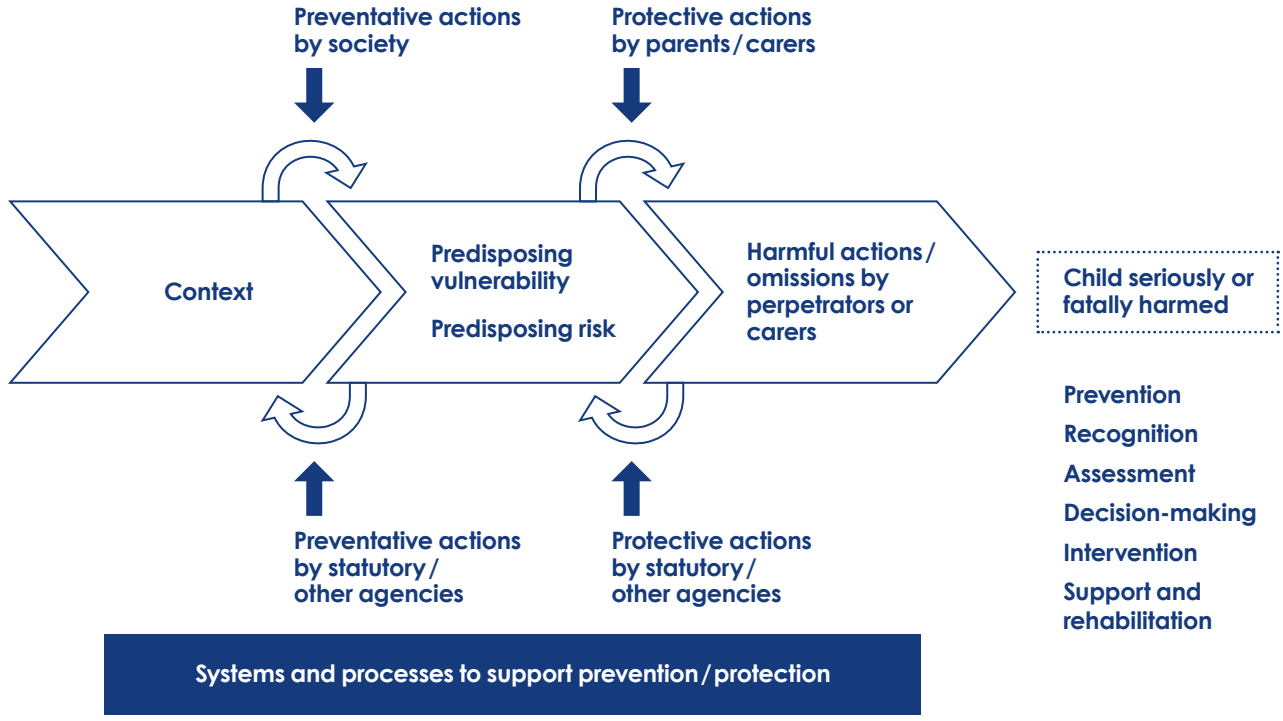
7 https://digital.nhs.uk/data-and-information/publications/statistical/child-death-reviews/2019/content

Key findings

3. Findings

3.1. The fieldwork for this review used the 'pathways to harm, pathways to protection' model of the 2011 to 2014 triennial review[8] as a framework for analysis of the findings (Figure 1). This was adapted in light of the emerging findings to make it specific to the context of SUDI in families with children at risk, incorporating a continuum of risk, and to develop a 'prevent and protect' model for responding to this challenge. The findings from the fieldwork and literature review will be presented in line with this overall model, first reflecting on the nature and circumstances of SUDI within the continuum of risk (section 4), then exploring learning in relation to local arrangements for promoting safer sleeping and reducing the risk of SUDI (section 5), before drawing out key learning (section 6) and presenting a proposal for a prevent and protect model (section 7).

Figure 1: Pathways to harm, pathways to protection[8]



8 P. Sidebotham, M. Brandon, S. Bailey, P. Belderson, J. Dodsworth, J. Garstang, E. Harrison, A. Retzer, P. Sorensen (2016). Pathways to harm, pathways to protection: a triennial analysis of serious case reviews, 2011 to 2014. DfE RR545. London: Department for Education.

4. What are the nature and circumstances of SUDI in families with children at risk?

Box 1: SUDI risk factors

- Unsafe sleep position (prone or side)
- Unsafe sleep environment:
  - co-sleeping in the presence of other risks (including bed sharing)
  - overwrapping (head covered, use of pillows or duvets)
  - soft sleep surfaces (soft or second-hand mattress)
- Tobacco – pregnancy and environmental exposure
- Alcohol and drugs – during pregnancy and when co-sleeping
- Poor post-natal care – late booking and poor ante-natal attendance
- Low birth weight (under 2,500g) and preterm birth (less than 37 weeks' gestation)

4.1. In the 40 cases of SUDI that we drew on, 21 of the infants were male (53%) and the majority (63%) were aged less than three months, with a peak at one month (Figure 2). This mirrors the typical pattern of SUDI cases.[9] Sixteen children were reported to be of White British ethnicity. Nine were from ethnic minority backgrounds. For 15, ethnicity was not stated.

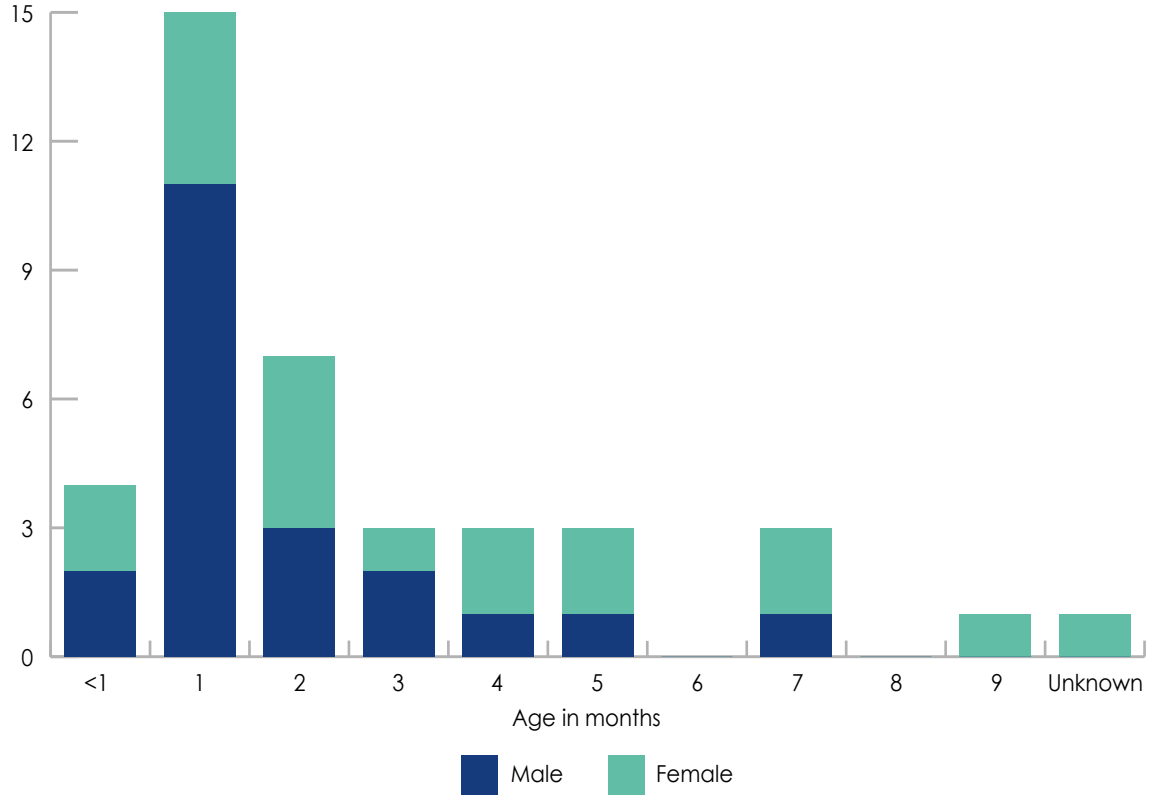
4.2. A range of pre-disposing risk factors were identified in the 40 notified cases (Figure 3). These were in keeping with the well-established evidence base for the risk factors associated with SUDI (Box 1).[10] Risk factors such as smoking in pregnancy were evident alongside key social and environmental factors (deprivation, overcrowding and adverse childhood experiences) that, in combination, are known to increase the risk of SUDI.[11] Focus groups of professionals on the fieldwork visits confirmed that the vast majority of families lived in deprived neighbourhoods, a finding in keeping with previous epidemiological

9 Carrie K Shapiro-Mendoza, Sharyn Parks, Alexa Erck Lambert, Lena Camperlengo, Carri Cottengim and Christine Olson. The Epidemiology of Sudden Infant Death Syndrome and Sudden Unexpected Infant Deaths: Diagnostic Shift and other Temporal Changes In: JR Duncan and RW Byard. SIDS Sudden infant and early childhood death: The past, the present and the future. University of Adelaide Press, 2018. Available online at: https://www.adelaide.edu.au/press/titles/sids

10 Lullaby Trust (2019). The Lullaby Trust: Evidence Base. https://www.lullabytrust.org.uk/research/evidence-base/

11 M. Bartick, C. Tomori, Sudden Infant Death and Social Justice: A Syndemics Approach. *Maternal Child Nutrition* 2019, 15 e12652. For the impact of overcrowding on SUDI, see P. J. Schluter, M. Hackett, R. P. K. Ford, E. A. Mitchell, Taylor P.J. Housing and sudden infant death syndrome. *New Zealand Med J* 1997; 140: 243 – 246. This retrospective study in the United States found that infants were placed on an unsafe sleep surface in a crowded living space even when there was a crib or bassinet in the house.

Figure 2: Age and gender of children



research.[12] Poor housing and overcrowding were evident in 10 of the SUDI incidents reported to the Panel. Unrecognised childhood adversity was a factor for a number of parents in the cases reviewed. There was a perception that parents with a background of adverse childhood experiences may be prone to a high degree of vulnerability during pregnancy, with mothers who had experienced abuse in childhood not being able to identify risks in their own relationships and closing off from engagement with professionals. Co-sleeping was found in 38 out of the 40 cases. Parental alcohol and drug use were common, as were issues related to parental mental ill-health, evidence of neglect and domestic violence.[13]

4.3. The 14 cases reviewed in depth, along with the wider group of 40 notified cases, demonstrated a continuum of risk. These risks related to the background context, predisposing vulnerability and risk, and specific situational risks, particularly related to out-of-routine incidents, all of which contributed to the circumstances in which the SUDI occurred (Figure 4, Table 1).

12 P. S. Blair, P. Sidebotham, P. J. Berry, M. Evans, P. J. Fleming. Major epidemiological changes in sudden infant death syndrome: a 20-year population-based study in the UK. *Lancet* 2006; 367: 314–19.

13 These factors were evident in 50% of the SUDI incidents reported to the Panel – a profile that is consistent with the study by J. Garstang and P. Sidebotham, Qualitative Analysis of Serious Case Reviews into Unexpected Infant Deaths, *Arch Dis Child*, 2018; 0:1-7.

Figure 3: Risk factors identified in the notified cases (n=40)

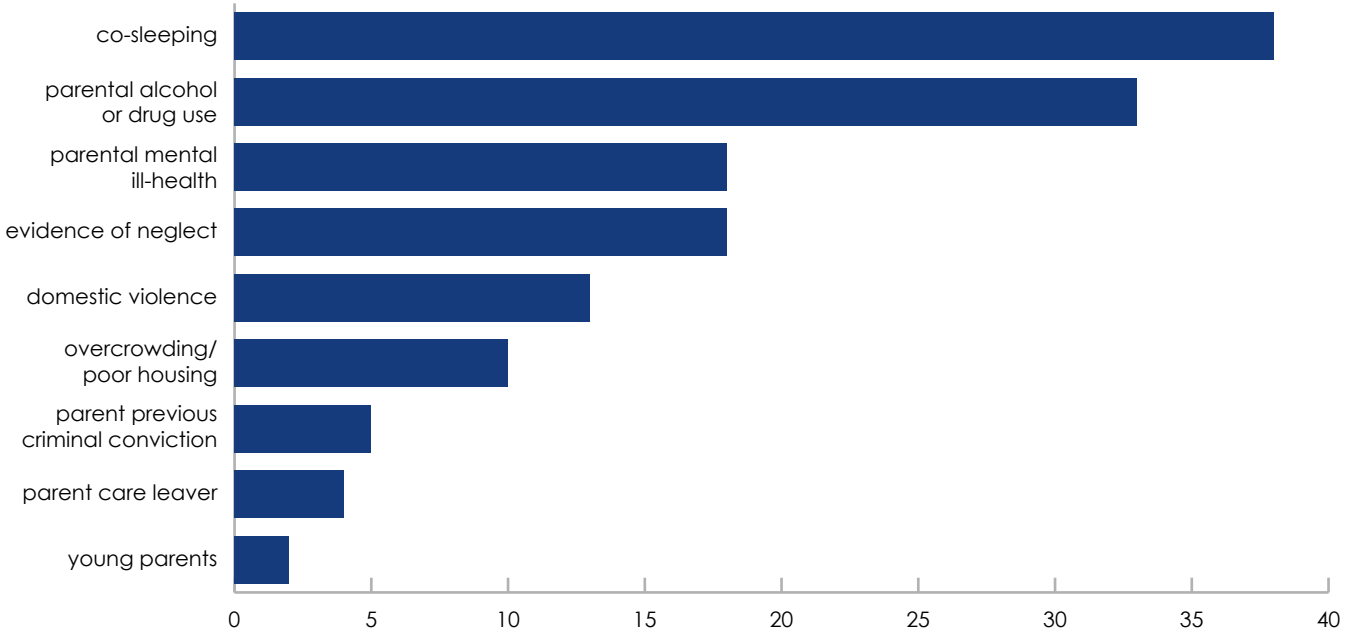


Figure 4: The SUDI continuum of risk

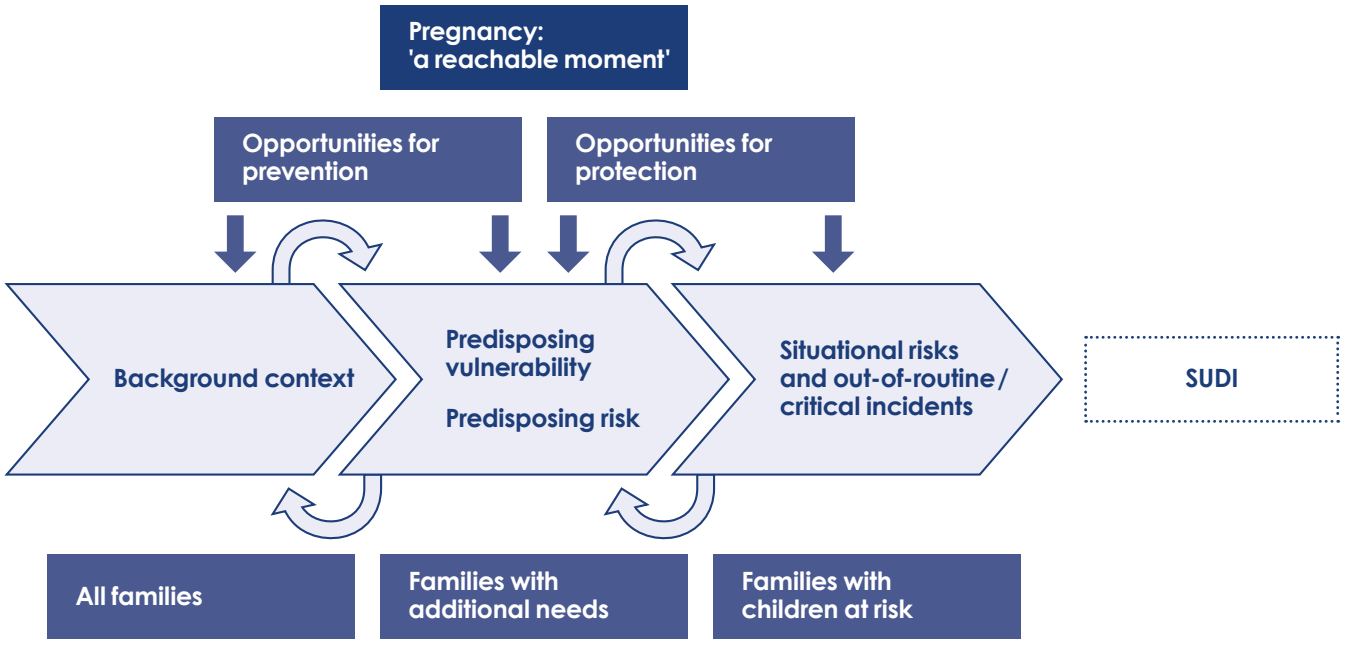


Table 1: The SUDI continuum of risk

Level of risk	Families affected	Risk factors identified in the fieldwork cases[14]
Background context	All families	• General recognised risk factors for SUDI • Variations in access to and range of preventive services • Fragmentation between providers
Predisposing vulnerability and risk	Families with additional needs	• Socio-economic deprivation • Poor or overcrowded accommodation • Adverse childhood experience of parents impacting on inability to detect harm in interpersonal relationships • Parental mental health problems • Alcohol or substance misuse • Ongoing and cumulative neglect • Parental criminal behaviours • Relationship breakdown and/or new partners • Limited engagement with services, including late ante-natal booking and mistrust of professionals • Prematurity or other vulnerabilities in the infant
Situational risks and out-of-routine incidents	Families with children at risk of significant harm	• Temporary housing • Change of partner • Altered sleeping arrangements • Alcohol or drug use on the night in question

4.4. All the 14 cases reviewed in the fieldwork demonstrated at least some of the background context risk factors, along with particular predisposing vulnerabilities and risks. Ten families were previously receiving services under child protection, child in need plans or care proceedings. Two families were known only to universal services before the SUDI. Situational risks and out-of-routine incidents were prominent: in 11 of the 14 reviewed cases, the last sleep was considered out of normal routine. In eight cases alcohol or drug misuse was noted at the time of the last sleep.

4.5. The hypothetical case profiles below are based on and typical of the 14 cases examined. They serve to illustrate the circumstances and key risk factors identified in the fieldwork. From all the cases we have seen as a Panel, and from reading and hearing about the cases in the fieldwork, it is striking how each one of these deaths could have been avoided through just a bit more vigilance in following safer sleeping advice. In none of the cases was there any suggestion that the parents had intended any harm to their child – on the contrary, most of these parents come across as devoted, loving

14 These risk factors reflect those found specifically from the review of the cases in the fieldwork. A much wider spectrum of risk factors for SUDI is recognised in the research literature.

and caring as any other parent. In many cases a change in routine, such as having to move to different accommodation, a family party, the arrival of a new partner or the baby being unwell, meant that the usual sleeping arrangements were not followed. In other cases, ongoing circumstances, such as parental mental health problems or alcohol or substance misuse, combined with previous experience or advice from others led parents to adopt unsafe sleeping practices as routine, perhaps believing that it wouldn't cause any harm to their baby.

Case 1: Baby W – universal services

A young mother became pregnant and made an early appointment for ante-natal care. She attended all ante-natal clinic visits, some with the father, and received universal care. She came into early labour and gave birth to a 36-week preterm male infant. Mother and baby were discharged home once feeding was established and the baby was seen to be healthy and gaining weight. The midwife and health visitor undertook home visits and found the mother tired but responsive to her baby. She and the father received safer sleep awareness advice that emphasised the risks posed by co-sleeping. One month following discharge, the family hosted a party at which alcohol was consumed. Mother became very tired and went to sleep with her baby in an armchair. She awoke next morning to find him lifeless and wedged between herself and the side of the armchair.

Case 2: Baby K – family with recognised risks – child in need plan

A single mother, whose two previous children had been removed from her care because of neglect, became pregnant and booked late.[15] The late booking prompted a referral to children's social care. The mother engaged well with the pre-birth assessment process. She disclosed domestic violence from the father and stated that he was no longer resident and the relationship had ended. She also discussed her cannabis use and agreed to attend a drug intervention programme. A child in need plan was initiated. Her baby, a girl, was born normally at term and discharged into her care. When the health visitor undertook a home visit, she found the house cluttered but in reasonable condition. She gave safer sleep awareness advice and felt that the mother had engaged with it. Following an evening of cannabis use at her home with the baby's father, the mother put her now two-month old baby to sleep in bed with her. She awoke the following morning to find her baby cold and lifeless.

4.6. The situational risks and out-of-routine incidents identified in the field work were also key findings in the literature review. The review explored the literature on how parents with an infant at high risk of SUDI make decisions for infant care, and what this can tell us about how to develop effective future interventions. Parents were often aware of the advice, but did not act on it for a variety of reasons. Disrupted routines were a common finding in SUDI cases and these often led to parents not

15 'Late booking' is a term used for an appointment for ante-natal care that is made very late (after 20 weeks of pregnancy). Midwives will explore the reasons for this with the mother and will make a referral to children's services with the mother's consent, unless there are significant child protection concerns.

following safer sleep advice, either because they were unable to, or because they did not consider it relevant in the circumstances. Models of intervention that rely 'solely on giving information are unlikely to produce meaningful change in this group' (Pease et al., 2020, p6). Parents often treated advice as a list of options, rather like a menu, from which you could choose the most appropriate items; thought the goal was to follow most of the advice most of the time, rather than all of the advice all of the time; and saw occasional risky scenarios as acceptable.

4.7. The literature review also identified a strong belief in maternal instinct as a protective factor that provided a reason to trade-off on following safety advice. Concerns about the infant's safety were often cited as a reason for co-sleeping, particularly in out-of-routine circumstances, such as when the baby was ill, or where parents were worried about possible intruders. The research team reported that:

> **"Reasons for not following the recommended advice often included beliefs about comfort, the need for night wakings to be as easy as possible and the impact of disruptions to the routine. Future interventions will need to acknowledge the complexity of infant care and support parents with planning for safety at every sleep… Tailoring safer sleep conversations within families' experiences may provide a platform for advice to be more acceptable."**
>
> **(Pease et al., 2020, p6)**

4.8. The literature review found that advice from 'a trusted, credible source', including 'partners, peers and wider family members' was particularly valued. Therefore, 'interventions that take a family approach rather than focussing solely on the mother or primary carer may be more effective' (Pease et al., 2020, p6).

4.9. One of the key findings from the literature review was the importance of plausibility in how advice is interpreted. Where parents are able to understand the mechanisms of risk (for example through accidental suffocation while sleeping on a sofa) they are more likely to trust the message and adhere to the advice, compared with advice for which they could see no logical mechanism.

4.10. A review of the Office of National Statistics (ONS) data for England and Wales and National CDOP data reveals that the SUDI cases notified to the Panel are similar to the wider picture of SUDI in the UK, many of which are associated with highly vulnerable families living in situations of social deprivation. In 2018/19, 3,250 child death reviews (of all ages) were completed. The majority (61%) concerned children under the age of one year. 325 deaths were categorised as SUDI, with modifiable factors identified in 195 (60%) of these cases. Until recently, there was no way of collating information on these cases to draw out learning from the child death reviews or compare the deaths reported to the Panel with all the child death reviews undertaken by CDOPs. This means that we did not have any way to check whether the cases notified to the Panel were complete and comprehensive, reflecting all SUDI cases in families with children at risk of significant harm, or representative of the wider cohort of

SUDI across the country. The development of the national child mortality database provides an opportunity for greater linkage between the learning from CDOPs and those from safeguarding partners. This provides the basis for our first national recommendation from this review (section 9).

4.11. In summary, the cases notified to the Panel and included in this review represent a sub-group of all SUDI cases. They involve families who are typically living within a context of recognised background risks, and for whom particular situational risks and disruptions to their normal routines mean that they are unable to engage effectively with safer sleeping advice. Decision-making within these families is influenced by a wide range of factors and sources, including other family members and mothers' own instincts and beliefs about their infant's safety. These findings point towards the need for a flexible and tailored approach to prevention with this group of families, which recognises and is responsive to the reality of people's lives, and is linked to plausible and understandable mechanisms for protection.

5. How effective are local arrangements for promoting safer sleeping and reducing the risk of SUDI?

5.1. This section sets out an evaluative commentary on the key aspects of local arrangements for promoting safer sleeping and reducing the risk of SUDI that were found on fieldwork visits. During the visits we found some examples of thoughtful, evidence-informed practice, with examples of creative and flexible partnership working. However, we also found wide variations and local inconsistencies in practice. While many areas were able to identify what constituted good practice – such as making the message specific for the context in which these families lived, evaluating these initiatives and always trying more innovative ways of engaging with families – these elements were often missing in the cases we reviewed.

5.2. Action to promote safer sleeping featured in CDOP reports and plans in all the localities visited. Local plans typically included:

- promotion of breastfeeding
- support for smoking cessation
- information for parents, including robust messages about risks from co-sleeping
- research to understand why safer sleep messages were not acted upon, particularly in vulnerable families
- briefing materials for professionals and multi-agency training about safer sleeping
- promotional activities associated with Safer Sleep Week

5.3. Safeguarding partners in the fieldwork areas had identified effective learning from serious case reviews and rapid reviews to initiate changes in key safeguarding processes such as pre-birth assessment, protocols for joint working between professionals (e.g. midwives and social workers), discharge planning and support for parents of preterm babies, and skills in working with high-risk families (e.g. motivational interviewing).

5.4. A number of safeguarding partners had related their action to prevent and reduce the risk of SUDI to wider strategies for promoting good outcomes for children. One example was the Leicester, Leicestershire and Rutland 'Strategy to Support Healthy Pregnancy, Birth and Babies'.[16] Such strategies brought together action to reduce poverty and health inequalities with systematic arrangements for

16 https://www.leicester.gov.uk/media/184822/strategy-to-support-healthy-pregnancy-birth-and-babies-in-leicester-leicestershire-and-rutland-2019-2024.pdf

prevention and early intervention to support vulnerable families.

5.5. The fieldwork visits identified examples of good practice and areas for improvement in relation to both preventive and protective actions. In addition, the literature review found evidence in relation to different types of intervention to reduce the risk of SUDI and improve engagement with services in families with children at risk. In the rest of this section we present the findings from the fieldwork using the 'pathways to harm, pathways to protection' model across the SUDI continuum of risk before presenting the findings from the literature review. First, we explore preventive work at a population level, protective work with families with additional needs and situational risks, and supporting families with children at risk to reduce the risks. We then go on to explore the evidence base for interventions to reduce the risk of SUDI in families with children at risk and interventions to improve engagement with services among these families.

Preventive work at a population level

5.6. SUDI is a sleep-related incident. The sleep environment is of primary importance and national guidance is definitive in recommending that during the first six months of life, an infant should be placed on their back to sleep, day and night, in a separate cot or Moses basket in the same room as the parents. Co-sleeping is common but potentially carries risks. These risks increase if either parent smokes or has consumed alcohol or drugs, and with co-sleeping on a sofa or armchair. This forms the core element of the national safer sleep advice for all parents produced by the Lullaby Trust in partnership with Public Health England and UNICEF.[17]

5.7. The Lullaby Trust materials were highly regarded and widely used in localities. Some safeguarding partners were proactive in undertaking local research to understand parental perspectives on ante-natal, neo-natal and post-natal care and support, including the content and process of safer sleep conversations and supporting materials. As a result, they had built on the national materials to produce local materials that sought to address particular contexts (for example, family celebrations, safer sleep during heatwaves and alcohol). Such material was seen to be helpful in enabling parents to reflect on infant routines and strategies to reduce risk.

5.8. However, the parents we spoke to highlighted that safer sleep messages were not always consistent, particularly on issues such as bed sharing.[18] They were critical that leaflets were too wordy and, in some cases, were poorly photocopied in black and white. There was a suggestion that better use could be made of social media to provide

17 Safer Sleep for Babies, The Lullaby Trust/Public Health England/UNICEF 2019.

18 Bed sharing is where the parent or parents sleep in the same bed as their infant. It is often done by mothers or caregivers to extend breastfeeding, to employ easy access to the breast for night feeding, and to foster bonding or physical closeness with infants. The research evidence, although contentious, suggests that the risk of SIDS as a result of bed sharing is considered to be low in the absence of other hazardous circumstances (P. S. Blair, P. Sidebotham, A. Pease, P. J. Fleming. Bed sharing in the absence of hazardous circumstances: is there a risk of sudden infant death syndrome? An analysis from two case-control studies conducted in the UK. *PLoS One* 2014; 9: :e107799).

information and 'nudge' parenting behaviour in relation to safer sleeping.

5.9. Some of the practitioners we spoke to said that the information for parents needed to be more direct and hard-hitting in explaining the consequences of an unsafe sleep environment. Research evidence suggests that parents are more likely to respond positively to safer sleep advice where they understand that there is a clear link between advice and risk. However, that understanding is less likely to be developed and embedded if it is presented as a list of dos and don'ts.[19]

5.10. There was a wide perception that pregnancy is a 'reachable moment' for midwives, health visitors and other professionals to engage parents. This provides opportunities for both reinforcing preventive work and for targeting appropriate protective work. The 'booking-in' process is a key opportunity to identify predisposed risk factors in relation to SUDI. This is also the occasion to consider the wider social and environmental circumstances of the mother and family. Additional needs may be met through targeted support or a referral for early help. Where there are more significant safeguarding concerns, a pre-birth assessment may be initiated.

5.11. However, while practitioners recognised the importance of pregnancy as a reachable moment, in a number of the localities visited they reported that the pressure from caseloads and the time constraints to cover a wide range of specified information at the appointment[20] meant that the opportunity to build relationships and explore vulnerabilities was more limited. This was particularly evident in areas of high social deprivation.

5.12. Some practitioners talked of neighbourhood deprivation as a 'new norm' that made judgements about situational risks problematic due to desensitisation.[21] In that situation late booking for ante-natal care and continuing to smoke during pregnancy were felt to be so prevalent as to place them below the threshold for referral for additional support.

Protective work with families with additional needs and situational risks

5.13. Discussions with practitioners on fieldwork visits indicated extremely variable levels of multi-agency awareness of and training about SUDI and safer sleeping. In some partnerships, professional guidance in relation to SUDI and safer sleeping was limited to those working in health visiting and midwifery. In other areas, the safeguarding partners had taken a much broader multi-disciplinary and multi-agency approach (Box 2). The review found good examples of awareness-raising materials on safer sleeping such as 'seven-minute briefings'. Some partnerships were beginning to incorporate

19 See Factors Influencing Maternal Decision-Making for the Infant Sleep Environment in Families at Higher Risk of SIDS: A Qualitative Study, A. Pease, J. Ingram, P. S. Blair and P. J. Fleming, University of Bristol, 2017.

20 For the detail of items to be covered by midwives at first booking appointment, see Ante-natal care for uncomplicated pregnancies, NICE guidance CG62, Appendix D. The specification for the mandatory ante-natal visit by health visitors is set out in guidance to support the commissioning of the Healthy Child Programme 0-19: Health visiting and school nursing services, Public Health England Commissioning Guide 2, pp.25-26.

21 This reflects a similar finding in M. Brandon et.al. 2020, Complexity and Challenge: A Triennial Analysis of SCRs 2014-17, pp.62-3.

awareness raising about SUDI and safer sleeping within other safeguarding training, for example in recognising and responding to neglect.

Box 2: Good practice examples

- Safeguarding partners in Salford developed high-quality, role-specific guidance materials available for practitioners in a wide variety of roles, including those working primarily in adult safeguarding.
- In Stockport, the local partnership carried out a survey with staff across the 'Stockport Family' multi-professional team to ascertain the current knowledge of staff about safer sleeping, and whether and when they had been trained. This feedback was used to design a bespoke programme of training for all staff.

5.14. The fieldwork cases highlighted the importance of risk assessment processes in relation to safer sleeping. Risk assessment should be an ongoing process, particularly when family circumstances change. Within this there are particular opportunities to review judgements about risk, for example:

- by midwives at booking and ante-natal checks
- by health visitors at the mandatory ante-natal and new birth visits
- at the six-week review with GPs
- by social workers and independent reviewing officers at child protection conferences, care plan meetings or review team meetings

5.15. We found examples of good-quality, timely pre-birth assessments that informed children in need planning, enabling a network of practitioners to establish a positive partnership with the mother and wider family. Good practice is for the pre-birth assessment to commence no later than 20 weeks into pregnancy and be completed no later than four weeks before the term date. This allows for sufficient time to undertake a full analysis of risk factors and family strengths, make decisions and put in place multiagency support. These timescales were not always met in the cases we reviewed and some assessments lacked sufficiently rigorous analysis of risk.

5.16. Some partnerships had developed a safer sleep risk tool for use in discussions with parents (an example is from Nottinghamshire Safeguarding Children Board). There was some interest from practitioners in the development of a national risk tool, perhaps linked to national multi-agency professional guidance. Systems and processes to support confident professional judgement in local areas would also be enhanced by incorporating safer sleep risk assessment and signposting within relevant policies, procedures and practice tools.

5.17. Within the framework of the 0 to 5 years phase of the Healthy Child Programme (HCP), the review found good examples of commissioned ante-natal classes and parenting support programmes in the community to complement the direct work with individual families by health visitors. Targeted support for families with additional needs was delivered through programmes such as the Family Nurse Partnership or locally designed provision, for example the Enhanced Health Visiting Offer programme

in Portsmouth, and SWANS (support for women ante-natal service) in Kirklees. These programmes were characteristic of the interventions to reduce the risk of SUDI cited in the literature review as described in paragraph 5.27 below. Safer sleep was addressed as part of infant care and safety, with intensive support from a trusted professional being a key factor. There was some variability in the criteria for accessing these programmes and the capacity to meet local need. Many localities reported that capacity was overstretched, particularly in meeting both the mandatory review requirements of the HCP and fulfilling a Universal Plus health visiting offer. Localities and stakeholders contributing to the review have highlighted the opportunity to address these issues as part of Public Health England's refresh of the high impact areas in the HCP (notably transition to parenthood and early weeks) and the specification for health visiting.

Supporting families with children at risk to reduce the risks

5.18. Families whose circumstances indicated high risk of significant harm were involved in 12 of the 14 cases reviewed in depth. In almost all these cases there was currently, or had previously been, statutory involvement (child in need plan, child protection, or care proceedings). Case visits have shown the need for work to promote a safer sleep environment to be more closely integrated with wider assessment and planning with the family to address safeguarding concerns.

5.19. Most incidents that were reviewed occurred when routine infant sleeping arrangements were disturbed by changing circumstances. This could follow a critical incident or a period of escalating safeguarding risk related to particular family events. They all involved co-sleeping and almost all were alcohol and/or drug related. A key question is the extent to which SUDI in out-of-routine circumstances, while not predictable, can nevertheless be made more preventable.[22]

5.20. The review found that in all cases safer sleep advice, including information leaflets, had been given to parents and documented, frequently on more than one occasion. Typically, such conversations took place as part of a health visitor's initial ante-natal visit and again at the new birth visit (when the safer sleep conversation would be logged in the Personal Child Health Record). Some partnerships were seeing safer sleep conversations as a staged approach to be built on, with relevant information and discussion at key points: ante-natal support, new birth visit and six-week assessment. Such an approach was intended to allow time for parents to absorb key information, ask questions and build understanding over a more extended period.

5.21. However, the evidence from research studies and in reviews commissioned by local

22 The 2011 to 2014 triennial review recommended an approach that steers away from trying to pronounce on whether a death or serious harm could have been predicted or prevented, to acknowledging that there is always room for learning and improvement in our systems. Such an approach recognises that there are many opportunities for prevention and protection, even without being able to accurately predict which children may be harmed, when or in what manner. P. Sidebotham, M. Brandon, S. Bailey, P. Belderson, J. Dodsworth, J. Garstang, E. Harrison, A. Retzer, P. Sorensen. (2016) Pathways to harm, pathways to protection: a triennial analysis of Serious Case Reviews 2011-2014. DfE RR545. London: Department for Education. p19.

partnerships suggests that parents do not always find such conversations meaningful. Some parents react negatively to a style of conversation that they perceive to be condescending or lecturing, and in which they experience strong pressure to comply with safer sleep messages.[23]

5.22. In the fieldwork cases, safer sleep conversations and risk assessments tended not to be sufficiently joined up with wider plans to work with the family in addressing safeguarding concerns and changing circumstances. Safer sleep conversations took place and were documented, but explicit safety goals in relation to the sleep environment were not evident in plans developed with the family. In a number of the localities, partners were seeking to address this issue, particularly by training health visitors, midwives and other professionals to develop a more 'coaching' approach to safer sleep conversations that combines empathy and support with appropriate challenge.

5.23. In the majority of the cases there were unexpected changes in family circumstances when the SUDI occurred. In some instances they were related to escalating safeguarding concerns that were not fully recognised by professionals working with the family (Box 3). In these cases the assessment of the sleep environment was typically treated as a discrete task within the plan for working with the family and not sufficiently linked to a wider understanding of the lived experience in the household.

Box 3: Missed opportunities to identify changing family circumstances in the fieldwork cases

- a previous referral about the family had not met the threshold for early help or children in need support
- a child in need plan had recently been closed as it was felt that previous safeguarding risks had been resolved
- over-optimistic assumptions about the family's capacity to change or maintain protective behaviours (particularly in relation to alcohol and substance misuse, or in maintaining restricted contact arrangements in a separated household)
- a lack of information about the infant's father or mother's current partner, particularly if there was a failure to disclose this information
- difficulties in transfer of information about the family and their social networks within and across agencies

5.24. Some safeguarding partners, following case reviews, had identified the need to focus safer sleep conversations and information on risk situations, and to initiate 'what if' discussions about arrangements to ensure a safer sleep environment. Research evidence with young mothers in economically-deprived communities indicates that such an approach may be more fruitful, not only with families of children at risk but more generally, as the propensity for bed sharing or sofa sleeping to occur in out-of-routine situations is evident

23 A. Pease, J. Ingram, P. S. Blair, P. J. Fleming. (2017) Factors Influencing Maternal Decision-Making for the Infant Sleep Environment in Families at Higher Risk of SIDS: A Qualitative Study. See also, for example: Findings of Insight Work 2019 – On Behalf of the Strategy to Support Healthy Pregnancy, Birth and Babies in Leicester, Leicestershire and Rutland. Leicester City Council.

across all family circumstances, not just those considered to be at high risk.[24]

5.25. Often a contributory factor was the reluctant and sporadic engagement between the family and practitioners. Many local areas were looking to promote a practice model in which practitioners sought to establish deeper and more open relationships with families as a basis for driving change and improving safety. Some local partnerships were seeking to incorporate work with families on safer sleeping into local strategies for responding to neglect, parental mental health concerns, domestic abuse and substance misuse.

Interventions to reduce the risk of SUDI in families with children at risk

5.26. The literature review identified five types of intervention aimed at reducing the risk of SUDI in families with recognised risks:

- infant sleep space and safer sleep education programmes
- intensive or targeted home visiting services
- peer educators/ambassadors
- health education/raising awareness interventions
- targeted health education messages using digital media

5.27. A number of characteristics of effective interventions were identified through the literature review. They are **'personalised, culturally sensitive, enabling, empowering, relationship building, interactive, accepting of parental perspective, non-judgemental and are delivered over time'** (Pease et al., 2020, p45). The best results were found when strategies to reduce SUDI risk were embedded within usual service provision, and when they began during the ante-natal period and continued through the post-natal period. Interventions need to be flexible and take account of the changing circumstances for parents as well as the developmental needs of the growing infant. 'Long-term provision (for example up to sixth post-natal month) builds on the initial contact and can provide both support for parents and opportunity for professionals to identify changes in sleep environment and infant care practices' that might increase risk of SUDI and SIDS, and to mediate those risks (ibid, p60). A key point in the success of interventions is that they should have 'a clear theoretical framework, [providing] a rationale for professionals to understand the relevance and utility of the intervention for their populations' (ibid, p5).

5.28. A number of interventions included the provision of a safer sleeping space for babies, such as a bassinette, 'Pepi-Pod' or 'Wahakura' (a traditional Māori woven basket). Studies showed that 'the majority of recipients did use the sleep space provided, immediately reducing the risk of the need to bed-share or use an alternative hazardous sleep environment' (Pease et al., 2020, p5). There is some evidence from New Zealand that these interventions have contributed to a reduction

24 A. Pease, J. Ingram, P. S. Blair, P. J. Fleming. (2017) Factors Influencing Maternal Decision-Making for the Infant Sleep Environment in Families at Higher Risk of SIDS: A Qualitative Study. 'Conversations with families that focus on the individual circumstances and endeavour to elicit their influences, beliefs and gently challenge their own instinctive views on optimal protective strategies may be necessary to support mothers with making safer infant care decisions.'

in infant mortality.[25] Programmes typically combined the provision of a safer sleeping space with other risk reduction measures.

5.29. Intensive and targeted home visiting programmes such as the Family Nurse Partnership have shown some evidence of improvements in preventable-cause mortality in the USA,[26] but this evidence is limited.

5.30. Some of the most promising interventions involve the use of peer educators, such as parents from within vulnerable communities or young people. Such programmes may engage and empower young and vulnerable parents and be achievable within communities that are traditionally considered 'hard to reach'.

5.31. Many programmes rely heavily on educating parents about the risks of SUDI. Such programmes may increase knowledge of the risks, but there is limited evidence of their impact on actual practice within families with children at risk. There is, at present, limited evidence on the use of technology to support safer sleeping, and the only studies to date have been in the United States.

Interventions to improve engagement with services in families with children at risk

5.32. The literature review found 'limited evidence for interventions to improve engagement in families with children considered to be at high risk of significant harm through abuse or neglect. Of the interventions which showed some benefit, these were all face-to-face programmes with high intensity family contact', such as the Nurse-Family Partnership, and with 'close working and co-ordination between agencies such as programmes that combined substance misuse treatment with parenting support' (Pease et al., 2020, p60). Engagement was found to be better where programmes could offer more flexible delivery and where they worked 'with local communities to promote and support the delivery of home visiting' (ibid, p5). Technology-assisted interventions were not effective. Barriers to engagement included:

> **"low motivation, feelings of shame and guilt, and stigma. The quality of the relationship between a skilled professional and family is key to engagement for meaningful change; this is not something that can be achieved in the short-term. Parent advocates, who have successfully navigated the challenges of child protection procedures, can be effective in working with parents and helping them to engage with professionals."[27]**

25 E. A. Mitchell, S. Cowan and D. Tipene-Leach, The recent fall in post-perinatal mortality in New Zealand and the Safe Sleep programme. Acta Paediatrica, 2016. 105(11): p. 1312-1320. S. Cowan, Their First 500 Sleeps. Pepi-Pod Report: 2012-2014. 2015, Change for our Children Limited.

26 D. L. Olds et al., Effect of home visiting by nurses on maternal and child mortality: results of a 2-decade follow-up of a randomized clinical trial. *JAMA Pediatrics*, 2014. 168(9): pp. 800-806.

27 Pease et al., 2020 p60

5.33. There is some evidence from the United States that motivational interviewing,[28] particularly when combined with a modular home-treatment programme, can improve engagement among families referred following child protection concerns. However, this has not been replicated in studies in the UK.

5.34. The literature review highlighted 'the importance of relationship-based practice and the characteristics of these relationships reported to be important: trust, non-stigmatising, and non-judgemental.' In addition, 'an approach that focuses on the wider needs of the family including housing and mental health needs' was found to be important (Pease et al., 2020, p60-1).

5.35. In summary, the fieldwork for this review identified a lot of thoughtful, evidence-informed practice, but also wide variations and inconsistencies in practice. At their best, local arrangements for promoting safer sleeping involved a range of professionals as part of a relationship-based programme of support that was embedded in wider initiatives to promote infant safety, health and wellbeing. The best programmes are flexible and able to respond to situational risks and out-of-routine circumstances. However, such approaches were patchy, and there were concerns that approaches to preventive work were not sufficiently attuned to the needs of the high-risk population, and that resource and time constraints meant that practitioners were unable to engage effectively with many of the most needy families.

5.36. Findings from the literature review were similar: 'targeted and long-term evidence-based interventions with continuity of service provider, delivered in the context of enabling parent-provider relationships has benefits for infants and families in both the short and long term' (Pease et al., 2020, p60). There was 'good evidence that multi-modal interventions that provide a safe infant sleep space with comprehensive face to face safer sleep education programmes are effective, delivering improvement across several key outcome measures for safer sleep and safe baby practices in vulnerable families' (ibid, p60). However, 'improving the engagement of vulnerable families is challenging and resource intensive. The most effective practices will involve professionals working with families regularly, over long periods of time to build trusted relationships; and for professionals and families to be linked with community-based support services' (ibid, p60).

28 Motivational interviewing is a behavioural strategy which aims to strengthen individuals' motivation to change, build commitment, promote decisions for positive change and increase self-efficacy.

Learning and recommendations

6. Key learning

6.1. Drawing on the findings from fieldwork visits, discussions with experts in the field and insights from the literature review, this section draws together key learning points that inform a proposed SUDI 'prevent and protect' practice model for local areas, reflective questions for safeguarding partners, and key national recommendations.

6.2. We have concluded that:

- A better understanding of parental perspectives by all professionals enables local areas to adopt a more flexible and responsive partnership with parents; develop supportive yet challenging relationships that facilitate more effective safer sleep conversations; and co-produce appropriate information and support for parents and carers to aid their decision-making about the sleep environment.
- There need to be better links between the work in local areas to reduce the risk of SUDI and wider strategies for responding to neglect, issues related to social and economic deprivation, domestic violence, parental mental health concerns, and substance misuse. This work needs to be embedded in multi-agency working and not just seen as the responsibility of health professionals.
- The use of behavioural insights and models of behaviour change should be investigated to explore whether these can support interventions to promote safer sleeping, specifically with this group of families with children at risk of significant harm. Approaches such as motivational interviewing hold out promise, particularly when combined with other strategies for family support and risk reduction. Such an approach could include the use of marketing and social media to influence behaviour change and could be linked to ongoing national work to provide consistent and evidence-based safer sleep messages as part of good infant care and safety.

Understanding parental decision-making about the sleep environment

6.3. Insights from the literature review have highlighted the importance of understanding the factors influencing decisions by parents, despite safer sleep messages stressing the dangers of co-sleeping and documented safer sleep conversations with health visitors and other professionals having taken place. Decisions to co-sleep may be described as pragmatic 'trade-offs' against the full implementation of safer sleep advice for a variety of reasons, including physical safety concerns for the infant, maternal instinct as a protective factor, and an occasional circumstance where routines were disrupted. Most research studies found that parents knew the safer sleep advice but found it unrealistic or implausible. Parents may take the view that because the cause of SUDI is not known, it cannot be prevented. The literature review suggested that where a reason for advice was lacking, parents were less likely to follow that advice; conversely, where they could see a clear link between the advice and an understandable mechanism of protection,

it was more likely to be followed. Four key conclusions follow:

- parents need advice from someone they trust and believe
- co-sleeping is both too common and too complex to apply a simple ban
- providing parents with plausible mechanisms of harm, such as a risk of suffocation when co-sleeping on a sofa, could improve trust in safer sleep messages
- planning for infant safety during disrupted routines might avoid rare but lethal scenarios

6.4. These principles are particularly important when working with families in challenging circumstances. As in all safeguarding work, practitioners working with such families must be able to exercise confident professional judgement in situations where there is complexity and ambiguity. A differentiated approach to the delivery of safer sleep advice and information is essential where there are pre-disposing risks and other vulnerabilities. Practitioners need to maintain an up-to-date view of the lived experience and current risks in families where there are concerns, and be responsive to any changes in their circumstances.

6.5. An approach based on the principles of authoritative practice[29] provides a robust framework within which practitioners can develop an understanding of what life is like for the family and how this informs work with the family to promote a safer sleep environment. Many areas have already developed models that share the characteristics of authoritative practice, using frameworks such as signs of safety, systemic practice or restorative practice as the theoretical underpinning. Characteristic features of authoritative practice include: maintaining a stance of respectful uncertainty; establishing facts and gathering evidence; triangulation of information; building chronologies; and recording the infant/child's perspective and situation. Practitioners are encouraged to question professionals in their own organisation and other agencies. Reflective supervision provides a setting to challenge 'framing' about a set of circumstances and the level of risk.

6.6. Reluctant and sporadic engagement between families and professionals was a notable feature in many of the cases that were reviewed. What professionals may sometimes perceive as 'non-engagement' may be better understood as 'closure'[30] – a response in circumstances such as social and economic deprivation or unresolved childhood adversity where an individual believes that what happens in their life is largely outside their control. Professionals may be seen as outsiders and not welcome.

6.7. Discussion at roundtable events emphasised the danger for professionals in wrongly attributing blame to such behaviour rather than recognising it as a situational risk that must be addressed. This has important implications for the approach to safer sleep

29 P. Sidebotham, M. Brandon, S. Bailey, P. Belderson, J. Dodsworth, J. Garstang, E. Harrison, A. Retzer, P. Sorensen (2016). Pathways to harm, pathways to protection: a triennial analysis of Serious Case Reviews 2011-2014. DfE RR545. London: Department for Education. pp200 ff.

30 P. Reder, S. Duncan, M. Gray. *Beyond Blame*, Routledge 1993.

conversations and the use of behavioural change models. Advice and information that is based on a model of personal agency (where an individual believes that events and circumstances are a consequence of their own behaviour) may be inappropriate in situations of social and economic deprivation where parents feel out of control in their own daily lives, and where they may not believe that anything they do will make a difference to what happens to their baby. Seeking to build trusted relationships with families in these circumstances may enable a better understanding of the way in which deprivation interacts with other risk factors in relation to SUDI, thereby creating a climate of change and improvement, working in partnership with the family.[31]

6.8. One crucial element in developing future programmes is that they should be developed and designed with the full and direct participation of parents/carers, partners, peers and wider family members. Preventive work must take parents' own experience into account and tailor the content of safer sleep conversations to each family's needs. Future interventions should also consider how they include partners, peers and wider family members to extend knowledge and understanding of safe sleep to all those who may be caring for a young baby.

Embedding SUDI risk reduction within a wider safeguarding context

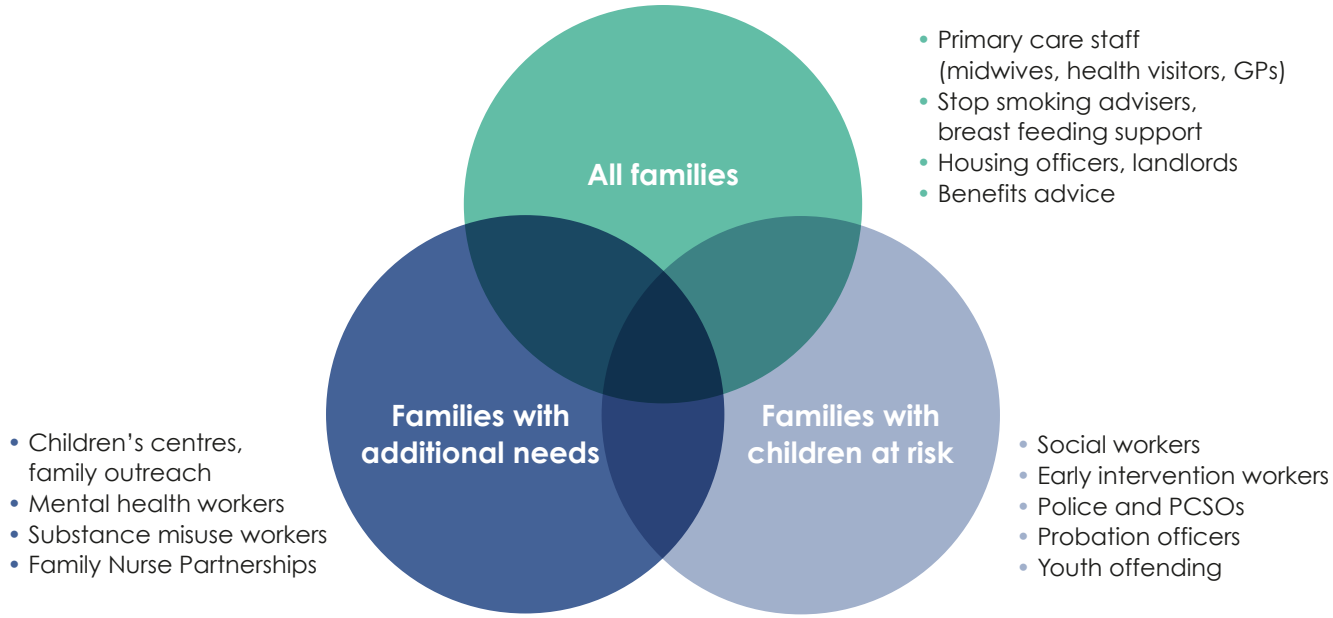
6.9. It is clear, both from our fieldwork and from the national analyses of serious case reviews, that the circumstances of many of these families are extremely complex and challenging. Typically, they are involved with a wide range of professionals from different agencies (Figure 5). This becomes increasingly the case as families move along the SUDI continuum of risk.

6.10. Co-ordinated multi-agency guidance and training can help promote a shared understanding about a safer sleep environment and enables practitioners to reflect on their individual role in promoting safer sleep messages and recognising risk. There are potential benefits in developing national guidance and risk tools to support this work in local areas. These include:

- promoting consistent information for practitioners about the factors associated with SUDI, based on current national and international evidence
- developing the knowledge and skills of practitioners to engage families in healthy lifestyle changes and parenting practices
- supporting effective safer sleep conversations, in which risk tools enable parents to assess the risk factors associated with their particular circumstances and make safe and appropriate decisions about the sleep environment
- outlining how individual organisations can promote safer sleep messages as part of their everyday work with families, with role-specific guidance for practitioners

31 As is pointed out in M. Brandon et al. 2020 p.62: 'practitioners should seek to understand the pathways through which socio-economic issues interact with other factors to influence parenting and outcomes for children. It is important neither to ignore the impacts of poverty, nor to simplistically attribute the family's problems to economic hardship.'

Figure 5: The SUDI continuum of risk: key professionals



6.11. It is particularly important that SUDI prevention is not treated in isolation from other aspects of infant safety, health and wellbeing. These families are at risk of a range of adverse outcomes, including child abuse and neglect, poor health and nutrition, as well as SUDI. Preventative and early help provision to respond to social and environmental factors forms a base on which to develop wider initiatives for prevention and protection. Practitioners from all agencies have opportunities to reinforce safer sleeping messages as part of wider promotion of infant health and safety. Keeping a focus on the needs and vulnerability of infants and children in the family is central to achieving this. Established risk-assessment tools such the Graded Care Profile (GCP-2) explore multiple areas of family functioning, but do not currently include SUDI risks. Adapting or updating these tools to include examples related to safer sleeping could provide a practical framework for practitioners.

Use of behavioural insights and models of behaviour change

6.12. During fieldwork visits and at the roundtable events, participants expressed interest in using behavioural insights and models of behaviour change (e.g. Behaviour Change Wheel COM-B)[32] to develop interventions to promote safer sleeping in these families. Such an approach could support the delivery of the high impact area of the Healthy Child Programme relating to the transition to parenthood and the early weeks. This could also be linked to wider national work to provide consistent, evidence-

32 See S. Michie et al. 2011. The Behaviour Change Wheel: A New Method for Characterising and Designing Behaviour Change Interventions. *Implementation Science* 6:42.

based safer sleeping message as part of good infant care and safety.

6.13. Effective intervention requires an understanding of how parental risk behaviours in relation to safer sleeping might be changed, and which aspects are important in achieving and sustaining a change in behaviour. The research evidence from reviewing behavioural change programmes with vulnerable families in the context of health suggests that a multi-faceted approach is required: combining action to address wider social factors arising from deprivation, the use of marketing and social media to influence behavioural change, along with key worker or peer support. Such initiatives are inevitably complex and require careful design and evaluation.[33]

33 For an overview of the approaches to behavioural change in public health and an evaluation of their application in relation to SUDI, see Preventative Strategies for Sudden Infant Death Syndrome, P. Sidebotham, F. Bates, C. Ellis and L. Lyus in *SUDI – Past, Present and Future*, pp.218-256, Ed, J. R. Duncan and R. W. Byard, University of Adelaide, 2018. Freely available for download at: www.adelaide.edu.au/press/titles/sids. Also, T. C. Salm Ward, and G. M. Balfour (2016). Infant Safe Sleep Interventions, 1990-2015: A Review. *J Community Health* 41(1): 180-196.

7. A proposal for a 'prevent and protect' practice model for reducing the risk of SUDI

7.1. The review found that the systems for working with families to prevent and reduce the risk of SUDI were complex. They included provision in line with the commissioning priorities and specifications for the Healthy Child Programme and interfaced with local arrangements for safeguarding children through early help and children in need processes. In taking this work forward, we are proposing a 'prevent and protect' practice model that recognises a continuum of risk of SUDI, with support and interventions that are differentiated to reflect the needs of all families, families with additional needs and families with children at risk, as shown in Figure 6 and Table 2 below. This framework could provide a basis for local safeguarding partners, working in conjunction with commissioners and other providers, to develop relevant, flexible and achievable strategies for reducing the risk of SUDI across the local population, and particularly among families with children considered to be at risk of significant harm.

7.2. Research evidence suggests that underlying social and environmental factors may have an effect on SUDI independently of risks such as low birth weight or smoking in pregnancy.[34] Accordingly, we have included socio-economic deprivation, overcrowding and adverse childhood circumstances within the pre-disposing risks of SUDI in our model. Timely and accessible preventative services have a key role in supporting families in these circumstances, particularly where there is enhanced home visiting and contact with a key worker or peer mentor to build trust and engage parents in making safe and appropriate decisions about the sleep environment.

34 See N. Spencer and S. Logan (2004) Sudden unexpected death in infancy and socioeconomic status: a systematic review. *J Epidemiology Community Health* 58: 366 – 373. This systematic review of 51 studies (to 1998) found that SUDI was associated with a range of adverse socio-economic determinants.

Figure 6: A prevent and protect practice model for reducing the risk of SUDI

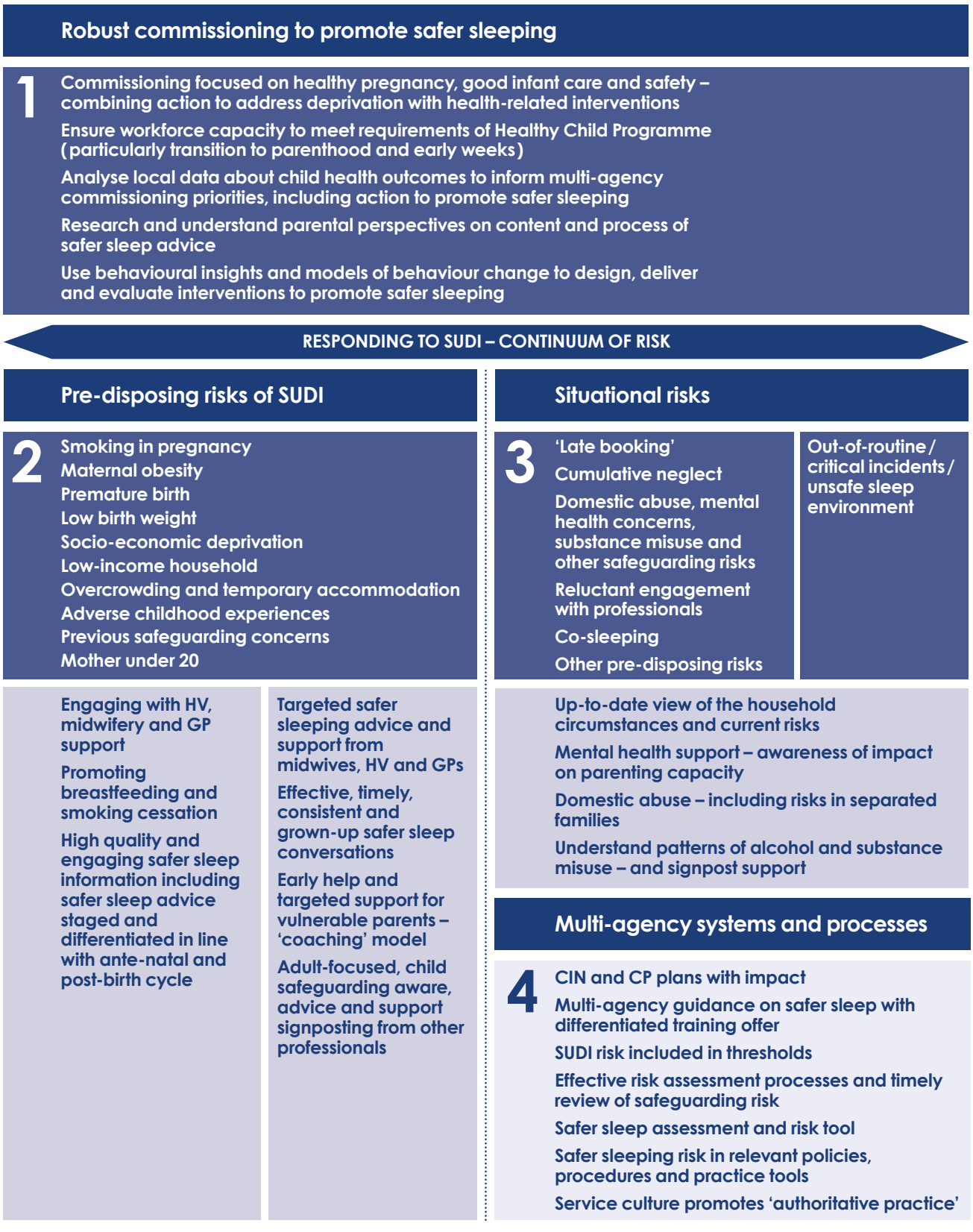


Table 2: Key features of the practice model

1	**Robust commissioning to promote safer sleeping within a local strategy for improving child health outcomes**
	• Safeguarding partners, in conjunction with commissioners and other local providers, incorporate action to reduce the risk of SUDI within a wider strategy to promote healthy pregnancy, good infant care and safety. • A comprehensive strategy will address social deprivation and associated health inequalities in particular communities, informed by up-to-date analysis of data, including feedback from parents. • Safeguarding partners will promote innovation, for example the use of behavioural insights and multi-faceted models of behaviour change. • Clear prioritisation will ensure funding and workforce capacity to deliver the local strategy.
2	**Multi-agency action to address pre-disposing risks of SUDI for all families, and with targeted support for families with identified additional needs**
	• Pregnancy is a reachable moment with families to identify pre-disposing risks of SUDI and signpost support, including targeted support. • Safeguarding partners need to consider: the format, quality and timeliness of information for parents; how parents can access support, including early help; the development of professionals' skills to establish authentic and sustainable relationships; and effective safer sleep conversations.
3	**Differentiated and responsive multi-agency support and challenge with families to promote safer sleeping in the context of safeguarding concerns and other situational risks**
	• Ensure that safer sleep advice and risk assessment are joined up with wider considerations of safeguarding risk and plans to work with families to address safeguarding concerns. • Link the promotion of safer sleeping and identification of unsafe sleep environments within local strategies for responding to neglect, reducing domestic violence, addressing parental mental health concerns and tackling substance misuse.
4	**Systems and processes that support effective multi-agency practice across the continuum of risk of SUDI**
	• Professionals are supported in 'authoritative practice' in working with families, particularly those at high risk of abuse or neglect. • There is comprehensive multi-agency professional guidance in relation to safer sleeping. • Indicators of risk of SUDI are included in multi-agency levels of need (thresholds). • Safer sleep risk is covered in relevant policies, procedures and practice tools.

8. Leadership and learning in localities

8.1. An effective local response to reduce the risk of SUDI – as with all safeguarding work – depends on the quality of local leadership, the culture that those leaders develop within and between their organisations, and the quality of joint working both by practitioners on the front line and strategically. While there is learning from this review that will need to be taken forward nationally, there is much that can and should be addressed in localities, for example through Health and Wellbeing Boards working closely with multi-agency safeguarding partners, or through other partnership arrangements.

8.2. In keeping with an ethos of supporting relevant local learning and development, we are encouraging local safeguarding partners to evaluate their current local arrangements against the practice model presented above, drawing on a series of reflective questions:

Understanding the views of parents about safer sleep information

- How well do we understand the views of parents about safer sleep information: format, accessibility, timing, key messages and 'conversations' with practitioners? How is this integrated with messages around normal infant care and safety?

Knowledge, understanding and skills of the workforce to promote safer sleeping within their role

- How far do practitioners in our workforce have the knowledge and understanding appropriate to their role to promote safer sleeping? How is this role integrated with a multi-agency response, if required?

Multi-agency systems and processes

- How is the recognition of unsafe sleep arrangements and risk of SUDI incorporated into multi-agency safeguarding procedures and practice tools for responding to neglect, domestic violence and abuse, children of alcohol and substance-misusing parents, and children at risk where a parent has a mental health problem?

Workforce capacity

- Is there sufficient workforce capacity to develop and maintain support for parenting (including safer sleep advice) with families with additional needs and for highly vulnerable families? If not, what initiatives have been taken to address this or work within the constraints?

Quality assurance

- How is the partnership assured about the effectiveness of its work to promote safer sleeping and reduce the risk of SUDI?

9. Recommendations

9.1. The important learning points from this review are incorporated into a proposed practice model that could form part of local initiatives for preventing and reducing the risk of SUDI. In addition, three national recommendations aim to provide effective support for professionals working with families with children at risk.

Recommendation 1

We recommend that the Child Safeguarding Practice Review Panel and the Department for Education work with the Department for Health and Social Care, NHS England and the National Child Mortality Database to explore how data collected through child death reviews can be cross-checked against those collected through serious incident notifications. The aim is to ensure consistency and rigour in both systems, and to explore how national learning from both systems can be most effectively disseminated and acted on at local and national levels.

Recommendation 2

We recommend that, as part of its refresh of the high impact areas in the Healthy Child Programme and the specification for health visiting, Public Health England considers how the learning from this review could be embedded within the transition to parenthood and early weeks. In particular, to consider how targeted multi-modal interventions that provide a safe infant sleep space with comprehensive face-to-face safe sleep education can be embedded in wider whole family initiatives to promote infant safety, health and wellbeing; and to consider how the implementation of these elements of the Healthy Child Programme can be expanded to involve practitioners from all agencies working with families with children at risk.

Recommendation 3

We recommend that the Department of Health and Social Care works with key stakeholders to develop shared tools and processes to support front-line professionals from all agencies in working with families with children at risk to promote safer sleeping as part of wider initiatives around infant safety, health and wellbeing. These tools and processes are intended to supplement the current evidence-based safer sleeping advice, to assist local areas in implementing effective preventive work. They could draw on the prevent and protect practice model to enable a flexible and responsive approach, and where appropriate, incorporate relevant and validated risk assessment tools.

9.2. Finally, we identify two areas where further research is needed to establish a stronger evidence base in relation to working with families with children at risk specifically to reduce the risk of SUDI.

Research focus 1

There is a need for practice-based research within this country to establish the efficacy of different interventions to reduce the risk of SUDI within families whose children are at risk. The literature review concludes that 'studies should use controlled observations taken from the same population and preferably as a randomised controlled trial. Where this is not possible, robust evaluations that use objective measures should be conducted' (Pease et al., 2020, page 8).

Research focus 2

There is a need for further research into the use of behavioural insights and models of behaviour change working with parents whose children are at risk to develop and deliver effective safer sleep messages and approaches. The use of such models should be thoroughly and carefully evaluated.

Conclusion

As stated in the foreword to this report, the sudden and unexpected death of an infant is one of the most devastating tragedies that could happen to any family. The fact that over 300 infants die this way each year in the UK, many in circumstances that could be prevented, is a cause for great concern. As this review has shown, although the advice around safer sleeping is well established and evidence-based, many families living in challenging circumstances are not managing to follow this advice. Through the literature review and field work, we have identified approaches with the potential to reduce the risks of SUDI. While there is still much to learn and further research to be done, we believe the proposed prevent and protect practice model offers a framework for local safeguarding partners to develop their services and support their front-line practitioners. We hope that, acting on the learning from this review, individual practitioners from all agencies will be able to work more effectively with parents and families, particularly those whose children are at risk of significant harm. Embedding safer sleeping advice in wider multi-agency initiatives recognises that this is not just about preventing sudden unexpected deaths, but part of a broader approach to promoting infant safety, health and wellbeing.

Appendices

Appendix A. Case visit criteria

From an audit of 40 serious safeguarding incidents relating to SUDI that were reported to the Panel between June 2018 and August 2019, a sample of cases for review visits was identified according to the following criteria:

1. SUDI where the child or family were previously identified as being at risk of significant harm
2. A range of circumstances indicating high risk of significant harm, including:
   - current or previous child protection or children in need plan
   - cumulative neglect
   - known misuse of alcohol or drugs
   - domestic violence or criminal behaviours
   - mental health problems deemed to present a risk to children's wellbeing
   - unsuitable housing or frequent moves of home
   - parents who were care leavers
   - other children removed from care or courts involvement
   - young parents
3. Other considerations, including:
   - parents who speak English as a second language
   - 'cross-border' working between local authority areas

In addition, two cases were selected where the family was known previously only to universal services.

The following safeguarding partnerships were visited:

- Dudley
- Kirklees
- Leicester
- Liverpool
- Medway
- Nottingham
- Plymouth
- Portsmouth
- Salford
- Stockport
- Walsall
- Wandsworth

The Rochdale Borough Safeguarding Children Partnership made a written contribution to the case review visit to Salford and provided overall evidence for consideration as part of the review fieldwork.

Appendix B. Specification for fieldwork visits

Purpose

To draw learning from the individual case, and any wider learning in the area, about how professionals working with high risk families can better support parents and carers so that safe sleep advice is embedded in parenting practice, thereby reducing the risk of SUDI.

Key principles

- The focus of the case visit is learning and improvement of national significance (that is, applied locally but relevant across all areas)
- The reviewers will establish a 'safe space' for professionals to contribute openly and honestly to a positive and constructive review process
- We recognise the complex circumstances in which professionals work together to safeguard children
- We value the views of parents/carers about how services were experienced and their contribution to learning and improvement

Visit format

The reviewer was accompanied by a note-taker from the DfE. They met key members of the safeguarding partners/London Safeguarding Children Board for a scene-setting discussion about the case and the work of the wider partnership. Following this meeting, there was a case discussion with a focus group of professionals who were directly involved with the case. The reviewer had a conversation with the parents/carers where feasible and appropriate. Partnerships were asked to provide a small number of background documents in advance of the visit.

Outcome

At the end of the visit, the reviewer provided oral feedback from the visit, highlighting in particular key points of learning to inform the national review.

Participating areas were invited to join a roundtable event at a later stage in the review process, where the reviewers discussed and 'tested' emerging findings from the case visits.

Key questions asked during the visits: safeguarding partners

- Are there examples of cases in the local area where interventions by professionals to promote safe sleeping practice in high-risk families have been effective? What can be learnt from these cases?
- As a result of this or similar cases in the area, have any changes been introduced in the way that safe sleeping practice is promoted with (a) all families and (b) families considered to be at high risk?
- What advice about safe sleeping practice is available for professionals? (Policies and procedures; assessment and risk tools;

assessment and referral pathway; threshold guidance.)

- How is the recognition of risk of SUDI and promotion of safe sleeping arrangements incorporated into multi-agency guidance on responding to neglect, hard to engage families, domestic violence and abuse, children of alcohol and/or drug misusing parents, and children at risk where a parent has a mental health problem?
- How are professionals across partner agencies supported to recognise risk of SUDI and have challenging conversations about safe sleeping with high-risk families?
- What safe sleeping advice is available for parents? How is this promoted? Have parents been consulted about 'what works' in terms of helpful advice and information?

Key questions asked during the visits: practitioners

- What happened in this case?
- Was there anything that could have been done differently by the professionals working with the family to ensure that parents and carers maintained safe sleeping arrangements?
- What can we learn from this case about the ways in which safer sleep advice is currently delivered to and received by high-risk families?
- As a result of this or similar cases in the area, have any changes been introduced in the way that safe sleeping practice is promoted with (a) all families and (b) families considered to be at high risk?
- In a number of cases that we are looking at, 'safe sleep advice' was given to the parents/carers on more than one occasion – but not acted upon. What makes for an effective safe sleep conversation with parents and carers in high-risk families? What are the challenges?
- What advice about safe sleeping practice is available for professionals? (Policies and procedures; assessment and risk tools; assessment and referral pathway; threshold guidance.)
- How can we ensure that risks related to safe sleeping are considered as part of wider early help/children in need/child protection planning, and work with vulnerable families in specific circumstances such as responding to neglect, domestic violence and abuse, children of alcohol or drug-misusing parents/carers, children at risk where a parent/carer has a mental health problem?
- Are there examples of cases in the local area where interventions by professionals to promote safe sleeping practice in high-risk families have been effective? What can be learnt from these cases?

Key questions asked during the visits: parents

- What happened?
- What support did they receive about safe sleeping?
- What support might have been helpful to enable them to maintain safe sleeping arrangements?

Appendix C. List of stakeholders consulted

We are grateful to all those who gave their time to help us think about these complex issues. As well as discussions with individual areas during our fieldwork, we held several roundtable events to test our findings.

We held two roundtable events in London and Sheffield, with representatives from the following local areas:

- Dudley
- Kirklees
- Leicester
- Liverpool
- Medway
- Nottingham City
- Plymouth
- Portsmouth
- Rochdale
- Salford
- Stockport
- Walsall
- Wandsworth

We held a roundtable for organisations with expertise in this area:

- Association of Directors of Public Health
- Family Nurse Partnership National Unit
- Hertfordshire County Council Children's Services
- Institute of Health Visiting
- Lullaby Trust
- National Child Mortality Database
- National Police Chiefs' Council
- NSPCC
- Ofsted
- Principal Social Worker Network
- Public Health England
- Redbridge CCG
- Royal College of Nursing
- University of Bristol – Bristol Medical School (PHS)

In addition, a separate event was held for the Institute of Health Visiting

We had individual meetings with:

- Department of Health and Social Care
- Hertfordshire County Council Public Health
- Public Health England

Appendix D. Literature review methods

Registration

The study protocol was registered with the International prospective register of systematic reviews, PROSPERO number: CRD42020165302

Selection

A systematic review was conducted in December 2019. Searches of eight relevant databases were carried out and titles and abstracts screened using our inclusion and exclusion criteria. Snowball searching (tracking citations) of included papers' reference lists and contacting networks of relevant professional organisations for unpublished studies (grey literature) yielded further papers for inclusion. In total, the titles and abstracts of 3,366 records were screened by four authors, with 10% double screening and a 97% agreement rate. Conflicts were resolved through discussion and examination of the full text.

Data extraction

Study quality was assessed with the Quality Assessment Tool for Diverse Study Designs (QATSDD) checklist. Relevant data from each area of the review were extracted into Excel for comparison, including study characteristics, design, outcome measures, type of intervention and how it was delivered.

Qualitative data were extracted into a matrix using Excel to conduct meta-synthesis of themes. Data from included studies were presented descriptively (variability in presentation precluded a meta-analytical approach).

Study synthesis

Interventions to reduce the risk of SUDI in high-risk families and interventions to improve engagement with services in high-risk families

Popay et al.'s framework for conducting narrative reviews is used to establish the following:

- Developing a theory of how the intervention works, why and for whom
- Developing a preliminary synthesis of findings of included studies
- Exploring relationships in the data
- Assessing the robustness of the synthesis

This framework aims to standardise narrative approaches to systematic reviews, where the primary synthesis comes from understanding how and why an intervention worked or didn't work, rather than meta-analysis, which is not possible in the current review. Narrative synthesis offers a systematic approach to evaluating both outcomes and processes in intervention studies and is therefore particularly relevant to the current review. Synthesis of engagement papers was conducted separately for quantitative and qualitative data, allowing for assessments of the type of interventions that might improve

engagement with services, and the factors which influence engagement.

Decision-making for the infant sleep environment in high-risk families

In order to conduct a meta-synthesis of the qualitative data, themes from included studies were extracted into an iterative framework. The framework was developed as themes were added, rather than being decided prior to data extraction. This was done to mirror the thematic approach taken by most qualitative research where data from interviews or focus groups is examined to look for patterns and commonalities rather than trying to make it fit a pre-existing model. In this way, the data extraction and synthesis took place concurrently for qualitative studies in the decision-making arm of the review.

Themes and subthemes as reported in papers were entered into a spreadsheet starting with the earliest publication date first, and initial themes were noted. As subsequent themes were added from each included study, new themes were identified and relationships between papers were examined. This approach was undertaken by two authors, with discussions ongoing to reach agreement about overall themes.

Appendix E. Glossary of terms

Bed sharing: Where the parent or parents sleep in the same bed with their infant. It is often done by mothers or caregivers to extend breastfeeding, to employ easy access to breast for night feeding, and to foster bonding or physical closeness with infants.

Co-sleeping: The practice of sharing a bed, sofa, armchair or other surface with an infant for sleep, which can take place intentionally or unintentionally.

Families with children at risk: Families whose circumstances indicate high risk of significant harm. For the purposes of this national review, the range of circumstances indicating high risk of significant harm included:

- current or previous child protection or children in need plan
- cumulative neglect
- known misuse of alcohol or drugs
- domestic violence or criminal behaviours
- mental health problems deemed to present a risk to children's wellbeing
- unsuitable housing or frequent moves of home
- parents who were care leavers
- parents who were care leavers
- other children removed from care or courts involvement
- young parents

Out-of-routine incidents: Unexpected changes in family circumstances immediately before SUDI, in which an infant is placed in an unsafe sleep environment. These situations occur across the full continuum of risk. In high-risk families they may be associated with situations where there is escalating safeguarding risk.

Pre-disposing risks: Factors that are strongly associated with the incidence of SUDI. Local interventions by partner agencies focus on modification of the risk through universal and targeted services.

Situational risks: Where an infant is at risk of significant harm as a result of neglect, domestic violence, parental mental health concerns or substance misuse. In high-risk families, these factors are present in combination with factors such as deprivation, worklessness and poor housing conditions. Work by partner agencies to reduce the risk of SUDI in these families often takes place within a framework of statutory intervention.

Sudden infant death syndrome (SIDS): The sudden death of an infant less than one year old that apparently occurs during normal sleep, which remains unexplained after a thorough investigation, including a complete autopsy, review of the circumstances of death and the clinical history (Krous et al., 2004). There are some cases in which there is no clear cause of death but in which the circumstances do not typically fit the criteria for SIDS. These are cases in which the history, scene or circumstances of death suggest a likelihood of asphyxia but in which positive evidence of such is lacking. Pathologists in the UK often use the term 'unascertained' for such cases, many of which are associated with risk factors such as co-sleeping and bed sharing that might have contributed to the death

Sudden unexpected death in infancy (SUDI): An unexpected death may be defined as the death of a child that was not anticipated as a significant possibility 24 hours before the death, or where there was a similarly unexpected collapse leading to or precipitating the events that led to the death (Fleming et al., 2000). SUDI refers to all unexpected deaths up to one year of age at the point of presentation. As such, it is a descriptive term rather than a diagnosis. At the conclusion of an investigation, they will divide into those for which we have a clear diagnosis, including those related to underlying medical causes, accidents and homicides (explained SUDI), and those for which we do not have a diagnosis (SIDS) (Sidebotham and Fleming, 2007).

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