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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

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Contents

Glossary and Abbreviations

Sudden Unexpected Death in Infancy (SUDI)	The death of a baby which was not anticipated as a significant possibility 24 hours before the death.
Sudden Infant Death Syndrome (SIDS)	“[T]he sudden unexpected death of an infant <1 year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation, including performance of a complete autopsy and review of the circumstances of death and the clinical history” (Krous et al. 2004 (1)).
Back to Sleep Campaign	A national UK campaign to encourage parents to place their infants on the back for sleep.
Bed-sharing	Sharing an adult bed with a baby where both the baby and the adult are asleep.
Co-sleeping	Sharing any sleep surface (beds, sofas etc.) with a baby where both the baby and the adult are asleep.
Cot death	An older term for Sudden Infant Death Syndrome.
Prone sleep	Refers to an infant sleeping on the tummy.
Mortality (Rate per 1000 live births)	The number of babies who died for every 1000 live births. E.g. a rate of 0.3 means 3 babies in every 10,000 live births.
Sofa-sharing	Sharing a sofa with a baby where both the baby and the adult are asleep.
Supine sleep	Refers to an infant sleeping on the back.
Pre-term	The birth of a baby at fewer than 37 weeks' gestational age.
Low birth weight	Babies who are born weighing less than 2,500 grams (5 pounds, 8 ounces).
CESDI	Confidential Enquiry into Stillbirths and Deaths in Infancy

CI	Confidence Interval
HR	Hazard Ratio
ICM	Intensive Case Management
IMR	Infant Mortality Rate
MI	Motivational Interviewing
NFP or FNP	Nurse Family Partnership (USA) or Family Nurse Partnership (UK)
NICU	Neonatal Intensive Care Unit
PCIT	Parent-Child Interaction Therapy
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QATSDD	Quality Assessment Tool for Studies with Diverse Designs
RCT	Randomised Controlled Trial
SAU	Services As Usual
UC	Usual Care

1. Summary

1.1. Background

Several characteristics have been associated with higher rates of sudden unexpected deaths in infancy (SUDI). In the UK, these include vulnerable infants (low birthweight, pre-term, multiple births and admission to NICU), young maternal age, smoking during pregnancy, male preponderance and lower socio-economic status. The age distribution of these deaths is also unusual peaking at 2-3 months of age rather than the expected susceptible period of most infant deaths shortly after birth (2). Many of the recognised risks of SUDI overlap with those of child maltreatment, and families with children who may be at risk of child abuse or neglect often face multiple vulnerabilities, including risks of SUDI (3). Observational evidence over the last 30 years has identified modifiable risk factors pertaining to the infant sleep environment, that if acted upon, could and in many cases have been shown to, reduce the risk of some infant deaths. These risks include placing infants to sleep on their side or front, using too many bedclothes, co-sleeping on a sofa or armchair, solitary sleep in the first 6 months and bed-sharing in the presence of alcohol, drugs, smoking or with a baby born with a low birthweight or pre-term birth. Improving the uptake of safer sleep advice in families with children at risk is likely to reduce deaths further, but recommendations about the most effective way to do this are lacking. Understanding decision making in this group and identifying specific components of interventions that are worthy of consideration may contribute to the design of a large scale, targeted approach to risk reduction in families where the children are considered to be most at risk of SUDI.

1.2. Population Definitions

When considering the literature in this area, it is important to distinguish between families with children considered to be at high risk of significant harm through abuse or neglect and families with children considered to be at high risk for SUDI. While there is some cross over, they are not synonymous and should not be conflated. The published literature on safer infant sleep does not allow us to identify and present advice that is solely specific to families with children considered to be at high risk of significant harm through abuse or neglect. Furthermore, we do not have evidence that approaches to this latter group need to be significantly different. We have therefore focussed the parts of our review that consider the literature on safer infant sleep on families with children considered to be at high risk for SUDI (which may include some of the wider group of families with children considered to be at high risk of significant harm through abuse or neglect).

Throughout this report, unless specified otherwise, we use the phrase "families with children at risk" to denote those families with children at risk of SUDI, or SIDS as per the definitions used by each study included in our review. Where we are referring to the Child Safeguarding Practice Review's aims, and in our review of interventions to improve engagement with services, we will specify the group as "families with children considered to be at high risk of significant harm through abuse or neglect".

1.3. Aim

This literature review was commissioned by the Child Safeguarding Practice Review Panel to investigate the evidence for how health professionals can best support parents with children considered to be at high risk of significant harm through abuse or neglect to ensure that safer sleep advice can be clearly understood and embedded in parenting practice. Therefore, this systematic review investigated three areas of the literature: interventions for improving the uptake of safer sleep advice in families with children considered to be at high risk for SUDI, interventions to improve engagement with support services in families with children considered to be at high risk of significant harm through abuse or neglect, and improving our understanding of the parental decision making processes for the infant sleep environment in families with children considered to be at high risk for SUDI.

1.4. Methods

Selection

A systematic review was conducted in December 2019. Searches of 8 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 are presented descriptively (variability in presentation precluded a meta-analytical approach).

1.5. Results

In total, 67 papers were included in the review, including 18 found through grey literature and snowball searches.

Interventions to reduce the risk of SUDI in families with children considered to be at high risk for SUDI

Twenty-three papers were relevant in the review of interventions to reduce the risk of SUDI in families with children at risk. Five types of intervention were identified:

1. Infant sleep space and safer sleep education programmes
2. Intensive or targeted home visiting services
3. Peer educators/ ambassadors
4. Health Education / Raising Awareness Interventions
5. Targeted health education messages using digital media

The main findings suggest:

- The most convincing evidence for interventions that work have a number of identifiable characteristics: they are personalised, culturally sensitive, enabling, empowering, relationship building, interactive, accepting of parental perspective, non-judgemental and are delivered over time.
- Embedding programmes within 'usual service provision' was reported to return best results.
- Interventions that begin during the antenatal period and continue through the postnatal period report stronger measures of success.

- Interventions that provide a safe infant sleep space found 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.
- Interventions that used community-based approaches or used peer educators to spread infant safety messages were identified as successful in achieving scale, reach and penetration into the social systems of vulnerable groups.
- More successful interventions take account of changing circumstances for parents and as the infant ages and their developmental requirements evolve.
- Interventions reported with a clear theoretical framework, provide a rationale for professionals to understand the relevance and utility of the intervention for their populations.
- Digital messaging interventions were less effective in encouraging behaviour change in parents.

Interventions to improve engagement with services in families with children considered to be at high risk of significant harm through abuse or neglect

Twenty-eight papers were relevant in the review of interventions to improve engagement with services in families with children at risk of significant harm through abuse or neglect. The different types of intervention included:

1. Home Visiting Programmes
2. Differential Response
3. SafeCare Home Treatment Programme
4. Motivational Interviewing
5. Technology Assisted Parenting Interventions

The main findings suggest:

- Studies of parental engagement in home visiting programmes found that retention in programmes could be increased by offering more flexible delivery of the Nurse-Family Partnership (NFP), and by working with local communities to promote and support the delivery of home visiting.
- Differential Response (DR) involves a more supportive approach for lower level child protection referrals; parents prefer DR compared to traditional investigative child protection procedures.
- Motivational Interviewing (MI), aiming to strengthen individuals' motivation to change, improved parental engagement in parent training programmes in families with children at risk of significant harm through abuse or neglect.
- Comprehensive substance misuse treatment programmes work across systems to co-ordinate health treatment and social care support for affected families. These show some increase in parental engagement, but this is less effective when parents are mandated by courts to attend such programmes.
- Technology assisted interventions did not improve engagement in parent training programmes for families with children at risk of significant harm through abuse or neglect.

Decision making for the infant sleep environment in families with children considered to be at high risk for SUDI

Sixteen papers encompassing 13 studies were synthesised. The synthesis was able to provide robust insights into how families with children considered to be at higher risk of SUDI make decisions for the infant sleep environment. The meta-synthesis produced six themes coming from all 16 papers. These were:

1. Knowledge as different from action
2. External advice must be credible
3. Comfort, convenience and disruption to the routine
4. Plausibility, mechanisms of protection
5. Meanings of safety, risk mitigation using alternative strategies
6. Parents' own expertise, experience and instincts

The main findings suggest:

- Families often knew the advice but did not act on it for a variety of reasons, and so interventions that focus solely on giving information are unlikely to produce meaningful change in this group.
- Families valued advice that was from a trusted, credible source. This included partners, peers and wider family members. Interventions that take a family approach rather than focussing solely on the mother or primary carer may be more effective.
- 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.
- Embedded within responses to safer sleep advice were scepticisms about how the advice conferred protection for an infant. The synthesis uncovered plausibility as a key factor in how advice is interpreted. Describing the mechanisms of protection connected to safer sleep advice may help parents' adherence by increasing trust in the messages.
- The studies described a wide variety of meanings of safety, and situations where parents/carers were trying to keep their infants safe, but inadvertently increasing the risk of SUDI. Interventions that educate parents on the physiological safety needs of a sleeping infant may be more effective at mitigating some of this inadvertent risk. Interventions that include a risk planning element should also be tested to see if unintended, unsafe bed-sharing can be avoided.
- Parents/carers used their own previous experiences of infant care to influence how they made decisions. They often trusted their own instincts where advice was not convincing enough. Tailoring safer sleep conversations within families' experiences may provide a platform for advice to be more acceptable.

1.6. Conclusions and implications

This review forms part of a wider project to review practices and make recommendations about how best to increase uptake of safer sleep advice in families with children considered to be at high risk of significant harm through abuse or neglect. For reasons stated above, we focussed the parts of our review investigating uptake of safer sleep advice on families with children considered to be at high risk for SUDI. Overall, we found evidence suggestive of how future interventions to improve safer sleep uptake should be designed and implemented for maximum impact in families with children considered to be at high risk for SUDI. The implications of this review are outlined for practitioners/interventionists, policy makers and future research, below.

For practitioners/interventionists

- A non-judgemental, culturally sensitive, personal approach is required for families with children at risk providing evidence-based advice so they can make decisions on how to keep their infants safe.
- Health professionals should be provided with consistent advice that can be delivered in plain English to families with plausible explanations as to why this advice will keep their infant safe.
- Interventions need to use a strong theoretical underpinning, where the underlying assumptions about the links between the intervention and behaviour are clearly stated. To support this, interventions should have clear explanations, considering the needs for parents/carers to be provided with credible advice that incorporates mechanisms of protection which are understandable and account for the changing needs of a sleeping infant.
- Ideally conversations should begin in the antenatal period when families are most reliant on the health provision being offered.
- Future advice and guidance to families with children at risk should take parents' own experience into account and tailor the content of safer sleep conversations to each families' needs. Planning tools that acknowledge complexity and encourage parents and carers to design strategies for risk minimisation during disrupted routines should be explored in future research studies.
- Most studies in our review focussed on mothers, but the qualitative synthesis in particular, identified the importance of others. Future interventions should consider how they include partners, peers and wider family members to extend knowledge and understanding of safer sleep to all those who may be caring for a young baby.
- Interventions should, ideally, be delivered face to face. Innovations that consider how to capitalise on peer to peer models where information can be shared within community networks may be of use in this context.

For policy makers

- Interventions for this group should be embedded within existing service provision, with clear explanations of how they are supposed to work for those delivering them.
- Continuity of care from the antenatal to the postnatal period is important. Health visiting and community midwifery provide ideal opportunities to have meaningful conversations with families continuing from the antenatal period through to the postnatal period. These conversations should follow the same underlying assumptions about how the intervention is supposed to work, to provide parents/carers with consistent and relevant information.

- There is some evidence that a service-wide approach targeting vulnerable families over a period of time can have direct impact on reducing infant mortality. Adequate time for health professionals to deliver safer sleep conversations should be provided and there was evidence that cuts to service provision make engaging families with support more difficult.

For future research

- New interventions should be developed and designed with the full and direct participation of parents/carers, partners, peers and wider family members, engaging the ‘nothing about us without us’ principle (4).
- Future intervention 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.
- Future research into the behaviour change techniques most applicable to safer sleep interventions in families with children considered to be at high risk may benefit from consideration of specific behavioural approaches such as the COM-B model of behaviour change (5).
- We found no evidence that supported the use of digital messaging or technology assisted interventions, although this was not the primary focus of our searches. With these types of intervention becoming more popular, and with the current SARS-COV-2 pandemic driving the need to find alternative support delivery options, future research should consider approaches to improve the effectiveness of digital health interventions for families with children considered to be at risk, and consult the literature on digital health intervention development.
- Approaches need to be flexible enough to allow health professionals to maximise on the trust and credibility they have developed with each family. Health professionals should be involved in the design and testing of future interventions in order to ensure their expertise is included.

2. Introduction

2.1. Rationale

SUDI in families with children considered to be at risk

A baby dying suddenly and unexpectedly is undoubtedly one of the biggest tragedies for any family. The ramifications spread to wider friends and relations, and to those health care professionals who supported them during pregnancy, birth and postnatally (6). Sudden and Unexpected Death in Infancy (SUDI) is the term used at the point of presentation and will include known causes of death such as unrecognised infection or underlying conditions. A majority of SUDI deaths cannot be fully explained despite full investigation and constitute Sudden Infant Death Syndrome (2). In the UK, the Office for National Statistics combine deaths registered as SIDS or 'Unascertained' to track 'Unexplained infant deaths'. In the UK, the rate of unexplained infant deaths has been steadily decreasing in the general population, from 0.52 per 1,000 live births at the turn of the Century to a low of 0.27 per 1,000 livebirths in 2017 (equating to approximately 200 deaths a year) (7). There is a stark inequity in the burden of these deaths, with the youngest parents living in circumstances of socio-economic deprivation experiencing the highest death rates. In 2017, the overall rate for babies born to mothers under 20 was 1.18 per 1,000 live births, more than 4 times the rate in the general population (7), at a time when the average age for first-time births is consistently increasing in the UK. A similar pattern appears for all families in lower socio-economic groups. In 2017 the rate for those in managerial or professional categories was just a third of the general population rate compared with a rate that was 50% higher than the general population among manual workers (7).

A recent thematic analysis of 27 SUDI cases leading to Serious Case Reviews from England between 2011 and 2014 (8) found families had complex social backgrounds, with 19/27 receiving support from social care at the time of death and 10/27 subject to child protection plans. Non-engagement with services was a prominent feature among these families along with long-term neglect and alcohol or drug misuse (16/27 deaths occurred with intoxicated parents co-sleeping with infants). Safer sleep advice to families was only documented in half of the families included in the review. The challenge in working with high-risk families is therefore not just sharing safe-sleep messages, but ensuring the evidence behind these messages is better understood, finding ways to engage parents in services, reducing neglect, improving overall parenting skills and tackling alcohol and drug misuse in early parenthood.

The Avon Infant Mortality Study (9) in 1987-1992, the CESDI SUDI study (10) conducted in 1993-6 and the SWISS study conducted 10 years later (2) provide most of the evidence base for the continued risk reduction campaign in England & Wales which has seen the number of unexplained infant deaths fall from nearly 1600 a year in the 1980s to just 183 deaths in 2017 (7). With this welcome fall has come a shift in the demographic characteristics of the families affected. Data from 300 consecutive SIDS deaths in Avon from 1984 to 2003 (11) showed that the proportion of deaths in families from deprived socio-economic backgrounds had risen from 47% to 74%, the prevalence of maternal smoking during pregnancy from 57% to 86%, and the proportion of pre-term infants from 12% to 34% in the bereaved families (11). SIDS infants now die at a younger age with more marked characteristics of vulnerability and to younger mothers (who were not yet born when the 'Back to Sleep' campaign was initiated in 1991). With the welcome reduction of infants dying in cots has come a proportional increase but an overall numerical fall (11) in bed-sharing deaths (an environment where prone positioning was always less common). We have since identified specific hazardous circumstances within this environment in which they occur; infants sleeping next to carers who smoke, who have consumed alcohol or drugs or share inappropriate surfaces such as sofas (2, 12). Working with UNICEF and The Lullaby Trust, the UK has adopted the strategy of acknowledging that bed-sharing happens and advising parents when it would be inappropriate to do so (13). With a continued fall in unexplained SUDI rates of a further 40% since 2000 in England & Wales this seems a better strategy than simply advising against bed-sharing which has had less effect on SUDI rates in the US (where SUDI rates have changed very little in the same period) (14).

Targeted intervention by health professionals may present an opportunity to reduce risks in some high-risk families. Other approaches that target specific high-risk behaviours such as the combination of alcohol or smoking and bed-sharing, or co-sleeping on a sofa, may also confer some protection for high-risk infants. A 2015 systematic review of safer sleep interventions highlighted the multiple approaches to changing parental behaviour, with a lack of evaluation and comparison groups limiting current knowledge of what works best for whom and under what circumstances (15).

2.2. Objectives

The aim of this systematic review is to use the existing literature to inform recommendations for how professionals can best support high-risk parents to ensure that safer sleep advice can be clearly understood and embedded in parenting practice. We have reviewed three areas of the literature: interventions to improve safer sleep practices in high-risk families, interventions to improve engagement with support services, and qualitative studies that explore how parents at high risk of SUDI make decisions for the infant sleep environment.

2.3. Research question

The research question proposed by the National Safeguarding Panel SUDI review is:

- In families 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 clearly understood and embedded in parenting practice so as to reduce the risks of SUDI?

With this in mind, specific research questions for each area of the literature review are:

- What safer sleep interventions have been tested with families with children at risk of SUDI and what can these tell us about what works to reduce the risk and embed safer sleep practices for this group?
- What can interventions to improve engagement between families with children considered to be at high risk of significant harm through abuse or neglect and support services tell us about improving uptake of effective safer sleep interventions?
- What does qualitative research tell us about the factors that influence decision making for the infant sleep environment, in families with children at high risk of SUDI, and how can we use this insight to improve intervention design and delivery?

3. Methods and Design

3.1. Registration

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

3.2. Eligibility Criteria

3.2.1. Population

As stated in the summary, we were careful to distinguish between families with children considered to be at high risk of significant harm through abuse or neglect and families with children considered to be at high risk for SUDI. We focussed our review on families with children considered to be at high risk for SUDI (which may include some of the wider group of families with children considered to be at high risk of significant harm through abuse or neglect). Our population comprised families with infants under the age of 1 year, at high risk of SUDI, however defined by individual studies. Inclusion criteria for what constituted "high risk" populations were wide due to the high variability of definitions within individual studies. We included all studies that took a targeted approach to intervention and included families with children at increased risk of SUDI.

3.2.2. Intervention or indicator

Interventions aimed at improving infant safer sleep practices and engagement with relevant health and social care services were included. Safer sleep interventions included were those which sought to influence the infant sleep environment, rather than those aimed at reducing risks such as stopping smoking or increasing breastfeeding. We therefore included interventions with an aim to have any impact on: infant sleep position, co-sleeping, bed-sharing, dummy/pacifier use, swaddling, room sharing, infant bedding, exposure to tobacco smoke in the home, or room temperature.

Similarly, qualitative studies investigating influences on decision-making were limited to those which covered topics pertaining to the infant sleep environment, as above.

3.2.3. Comparator

In studies testing an intervention, the comparator was expected to be either standard care or a less intensive version of the intervention.

3.2.4. Outcomes

Outcomes reported were often proxy measures such as reported safer sleep practices. Objective measures such as video monitoring were also included and described. Themes from qualitative studies were extracted and synthesised.

3.2.5. Report characteristics

Searches did not limit by date, language or country. At full text screening, included studies were limited to those from Western Europe, North America or Australasia due to substantial cultural similarities and the fact that most of the observational research in these countries has been shown to be broadly relevant in the others. Interventions were limited to those from the last 15 years due to the changing nature of infant care products and practices. Unpublished reports were included where they met the inclusion criteria and included data on the results of the study. Reports describing interventions but where no outcome data were reported were excluded.

3.2.6. Exclusions

The following served as exclusion criteria:

- Papers relating to explained non-sleep causes of death, for example infections or metabolic disorders found at postmortem. (Wrong outcome)
- Studies describing interventions for the general population with no high-risk targeting (wrong population)
- Studies describing interventions not related to safer sleep or the sleep environment (wrong outcome)
- Interventions that took place pre 2005 (too old)
- Studies describing effectiveness of alcohol/drug services without primary outcomes relating to engagement (no engagement primary outcome)
- Studies describing decision-making for infant care not related to safer sleep (wrong outcome)
- Studies describing decision making for infant care in the general population with no high-risk group (wrong population)
- Studies describing decision making for infant care not using qualitative research methods (wrong study design)
- Studies based in countries other than Western Europe, North America or Australasia (wrong population)

3.3. Information Sources

Searches of the following 8 online databases took place between 20-29 December 2019.

- Medline via Ovid SP: 1946 to present
- CINAHL (nursing and allied health literature database)
- Embase via Ovid SP: 1974 to 2019 week 52
- PsychINFO
- Cochrane Central Register of Controlled Trials (CENTRAL)
- International Bibliography of the Social Sciences (IBSS)
- Web of Science
- ProQuest Dissertations and Theses

Additional searches were conducted in January 2020 by emailing all English Child Death Overview Panels, Designated Doctors for Child Death, Designated Doctors for Safeguarding, UK local safeguarding children's partnerships, and the membership directory of The International Society for the Study and Prevention of Perinatal and Infant Death, a global non-profit organization of researchers, health professionals and parents. Snowball searches of included and relevant papers' reference lists were also carried out.

3.4. Search Strategy and selection process

Initial scoping of search terms by four authors refined a final list for inclusion in each search by assessing the first 30 titles and abstracts in Medline for relevance and other terms. Key search concepts included infant mortality terms and high-risk demographic terms. These were combined with intervention terms OR engagement terms OR decision-making terms to cover three aspects of the review. Table 1 shows an example search. Titles and abstracts were deduplicated in Endnote and imported into Rayyan, online screening software (https://rayyan.qcri.org/). Four authors (AP, JG, DW, CE) initially screened all titles and abstracts using the inclusion and exclusion criteria, with conflicts resolved by discussion and examination of the full text. Secondary screening of full text articles was completed by the same four authors, leading to final group discussions for included papers.

Table 1: Example search with key terms

Aspect	Keywords/free text	Example controlled vocab terms (MeSH, Emtree, CINAHL Headings, PsycINFO Thesaurus)
SUDI terms (Intervention and decision-making searches)	Sudden Infant Death*.mp	Exp Sudden Infant Death/
	SIDS.mp	
	SUDI.mp	
	SUID.mp	
	ASSB.mp	
	Accidental Suffocation and Strangulation in Bed.mp	
	(Asphyxia not birth asphyxia not perinatal asphyxia).mp	Asphyxia/
	(Unexpected death* not SUDEP not epilepsy).mp	
	Sleep-related death*.mp	
	Crib death*.mp	
	Cot death*.mp	
	Unexplained infant death*.mp	
High risk groups (Intervention and decision-making searches)	Child abuse.mp	Child abuse/
	High risk*.mp	
	Vulnerab*.mp	
	Socioeconomic factor*.mp	Exp Socioeconomic factors/
	Adverse Childhood Experience*.mp	Exp Adverse Childhood Experiences/
	Social Marginali#ation*.mp	Social Marginalization/
	Child neglect*.mp	
	Child maltreatment*.mp	
	Substance-related disorder*.mp	Exp Substance-related disorders/
	Preventive Health Service*.mp	Exp Preventive Health Services/
	Parenting.mp	Parenting/
	Maternal deprivation.mp	Maternal deprivation/
Intervention (Intervention search)	Intervention*.mp	
	Risk reduction*.mp	

	Injury prevention*.mp	Accident prevention/
	Health education*.mp	Exp Health education/
	Health behavio?r*.mp	Exp Health Behavior/
	Education*.mp	
	Infant equipment*.mp	Exp Infant equipment/
	Printed education* material*.mp	
	Maternal behavio?r*.mp	Exp maternal behavior/
	Parent* education*.mp	Caregivers/ed
Child abuse (engagement search)	Child abuse.mp	Child abuse/
	Adverse Childhood Experience*.mp	Exp Adverse Childhood Experiences/
	Social Marginali#ation*.mp	Social Marginalization/
	Child neglect*.mp	
	Child maltreatment*.mp	
	Maternal deprivation.mp	Maternal deprivation/
	Child welfare.mp	Child welfare/
Substance abuse (engagement search)	Substance-related disorder*.mp	Exp Substance-related disorders/
	Alcohol*.mp	Exp Alcoholism/
	Drug misuse.mp	Exp Drug Misuse/
	opioid-related disorder*.mp	
	Substance use*.mp	Exp alcohol drinking/
Parenting (engagement search)	Parent*.mp	Parenting/
	Parent child relation*.mp	Exp parent-child relations/
Prevention or Treatment services (engagement search)	Substance abuse treatment cent*.mp	Exp Substance abuse treatment centers/
	Child health service*.mp	Exp Child health services/
	Community mental health*.mp	Community mental health services/
	Mental health service*.mp	Exp Mental health services/
	Maternal health service*.mp	Exp Maternal health services/
	Prevent??ive Health Service*.mp	Exp Preventive Health Services/
	Health services accessibility.mp	Exp Health services accessibility/
	Social work*.mp	Exp social work/
Engagement/compliance (engagement search)	Engag*.mp	
	Patient participation.mp	Exp patient participation/
	Patient compliance.mp	Exp patient compliance/
	Treatment adherence.mp	Exp "Treatment adherence and compliance"/
	Treatment compliance.mp	

	Treatment readiness.mp	
	Professional patient relation*.mp	Professional-patient relations/
Infant care (decision-making search)	Safe sleep*.mp	
	Sleep*.mp	Exp Sleep/
	Infant car*.mp	Exp Infant care/
	Safe infant sleep*.mp	
	Safe to sleep.mp	
	Sleep* position.mp	
	Supine position.mp	
	Infant safe sleep*.mp	
	Bedshar*.mp	
	Co-sle?p*.mp	
	Room shar*.mp	
AND decision making (Decision-making search)	Decision*.mp	
	Influenc*.mp	
	Understand*.mp	
	Reason*.mp	
	Attitude*.mp	
	Belief*.mp	

3.5. Data Collection and Extraction

Included full texts were sourced either online or directly from corresponding authors, all included texts were successfully sourced. A data extraction template for all papers was piloted and refined using 9 included papers of different study designs. The final form included fields for author's names, year of publication, study design, country, sample size, target population, type of outcome, comparator, outcomes measured and effectiveness. Specific fields for qualitative studies included method of analysis and broad topic categories. Intervention mode of delivery was extracted using variables influenced by Michie et al's Mode of Delivery Taxonomy (5) and collected data on whether interventions were: face to face, on printed material, digital, used equipment, delivered individually, in groups, involved one-way or two-way interaction, and whether they were tailored.

3.6. Study Quality Assessment

The quality of all included studies was assessed using the Quality Assessment Tool for Studies with Diverse Designs (QATSDD) (16). This approach was developed specifically for review questions where the evidence addressing a research question uses a variety of different study designs. The tool is for use across both quantitative and qualitative research designs, which allowed us to assess the quality of studies comparatively across all included studies in the review. Four team members (AP, JG, DW, CE) scored each paper from 0-3 on either 14 or 16 items (depending on study design) and converted each score into a percentage. Included papers of the author's own work were independently rated by another team member. Scores and percentages are reported. Given the expected paucity of data in this field studies were not excluded based on quality assessment but limitations to the findings are discussed where necessary.

3.7. Study Synthesis

3.7.1. Interventions to reduce the risk of SUDI in families with children considered to be at risk and Interventions to improve engagement with services in families with children considered to be at high risk of significant harm through abuse or neglect

Popay et al's framework for conducting narrative reviews is used to establish the following (17):

- 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 did not 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.

3.7.2. Decision making for the infant sleep environment in families with children considered to be at risk of SUDI

In order to conduct a meta-synthesis of the qualitative data, themes from included studies were extracted into an iterative framework (18). 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 are 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 (AP and CE), with discussions ongoing to reach agreement about overall themes.

4. Results

4.1. Study Selection

A total of 3506 titles were sourced via the online database searches. A further 42 studies were sourced using grey literature searches (including requests from external organisations), and snowball searches looking through reference lists of included papers. Four authors (AP, JG, DW, CE) independently screened titles and abstracts of 3367 records, with 10% double screening (324 records) and a 97% agreement rate. Conflicts (24) were resolved through discussion and examination of the full text. Duplicates identified at the full text screening stage were conference abstracts from studies that were included as full text papers. A flow diagram with exact numbers included and excluded at each stage is shown in Figure 1. A total of 67 papers were included in the review, split by topic area: 16 in decision-making, 23 interventions to improve uptake of safer sleep advice and 28 interventions to improve engagement with support services.

4.2. Quality Assessments

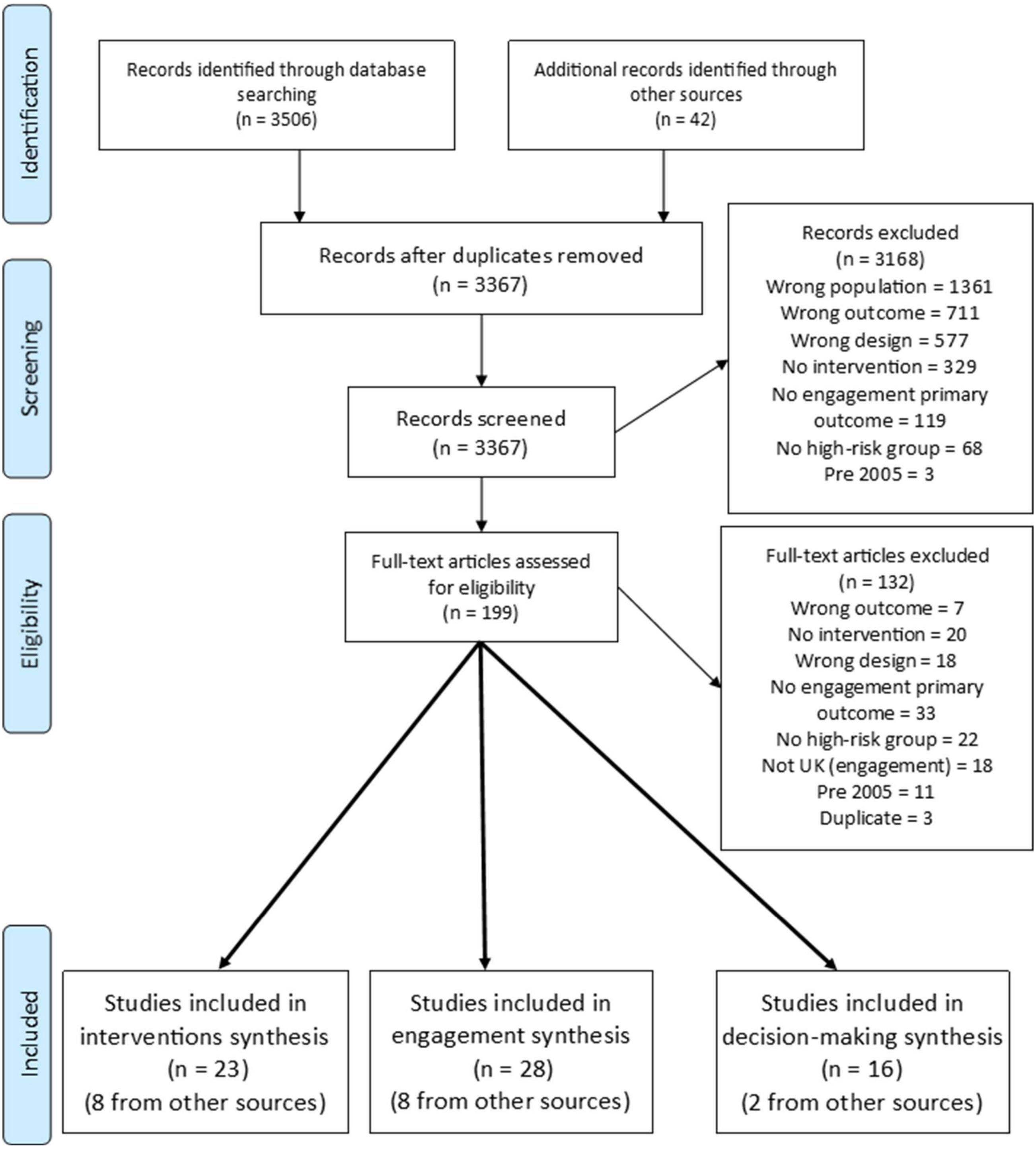
The Quality Assessment Tool for Studies with Diverse Designs (QATSDD) was applied for each included study (16). The tool scores quantitative and qualitative studies from 0-3 across 14 items, and mixed methods studies from 0-3 across 16 items. Scores out of 42 or 48 were converted to percentages for comparison across study designs. Individual paper scores and percentages are shown in Tables 2-5.

Across 23 papers describing interventions to reduce the risk of SUDI in families with children considered to be at risk, scores ranged from 10-35, with percentages ranging from 24%-83%; 3/23 studies scored under 50%, 17/23 scored 50-75% and 3/23 scored over 75%. No papers were excluded from the narrative synthesis based on their quality assessment score.

Across 28 papers describing interventions to improve engagement with services in families with children considered to be at high risk of significant harm through abuse or neglect, scores ranged from 8-45, with percentages ranging from 19%-94%. 5/28 studies scored under 50%, 11/28 scored 50-75% and 12/28 scored over 75%. No papers were excluded from the narrative synthesis based on their quality assessment score.

Across 16 papers describing qualitative studies of decision making for the infant sleep environment in families with children considered to be at risk of SUDI, scores ranged from 19-42, with percentages ranging from 45-100%. 1/16 study scored under 50%, 8/16 scored 50-75% and 7/16 scored over 75%. No papers were excluded from the meta-synthesis based on their quality assessment score. For these 16 papers, after analysis, weaker studies were compared with stronger ones to look for differences in theme contributions and none were found.

Figure 1: PRISMA Flow Diagram of literature search and selection process



4.3. Study Characteristics

4.3.1. Interventions to reduce the risk of SUDI in families with children considered to be at high risk

Twenty-three papers evaluating interventions with populations identified as vulnerable were included and are grouped by intervention type and described in Table 2, below. From these 23 publications, over half of the studies (14/23) were conducted in the USA (19-32), four in New Zealand (33-36), three in the UK (37-39), and two in Australia (40, 41). The studies span 14 years from 2005 – 2019 and the overall quality scores ranged from 23.8% to 83.3%, with 18/23 papers scoring above 57%. The paper scoring 23.8% was a short descriptive digest, a 'case study' of good practice describing the intervention and key outcomes, rather than a research paper. The majority of studies were quantitative, eight were randomised controlled trials (22, 26-29, 33, 36, 40) and six were evaluations (19, 20, 23, 34, 35, 38); the remainder were mixed methods or used a variety of quantitative approaches. Three studies utilised the same data set (22, 27, 28), but presented different outcomes. The number of participants ranged from 7 (35) to 6515 (25), with some studies reporting participant numbers relevant to different elements of the study, for example in non-paired pre/post-test designs (30), studies including follow up data (25, 34) or studies reporting on different aspects of the study (31).

The majority of participants were pregnant women, mothers or families identified to have some vulnerability or characteristics that increased risk of SIDS to their infants. Seven studies recruited on ethnicity alone (19, 21, 22, 27, 28, 36, 41), while the remaining 16 studies recruited from populations with increased risk factors for SUDI and/or SIDS (20, 23-26, 29-35, 37-40).

4.3.2. Interventions to improve engagement with services in families with children considered to be at high risk of significant harm through abuse or neglect

In order to synthesise the engagement papers, quantitative (n=17) and qualitative (n=11) studies are described separately.

Quantitative Engagement Papers

There were 17 studies including quantitative data on interventions to improve engagement in families with children considered to be at high risk of significant harm through abuse or neglect. The quality of these studies was generally high with 13/17 scoring> 66% of critical appraisal and 8/17>75%. The majority of studies were carried out in the USA (14/17), with two from Canada and one from the UK. The key characteristics of included studies is shown in Table 3, below.

Qualitative engagement papers

Eleven qualitative studies were considered, with five of these using mixed methods- reported below are the qualitative insights on engagement only. Nine were USA based studies, one from England and one from Canada. In five of the studies it was possible to determine an effect on parental engagement, although size of the effect was not possible to determine. Using the QATSDD tool the quality assessments within these eleven studies ranged from a low score of 19% to 95% with 7/11 scoring > 66% of critical appraisal and 5/11>75%. As such the quality of these studies was deemed to be quite mixed. Study characteristics are shown in Table 4, below.

4.3.3. Decision making for the infant sleep environment in families with children considered to be at high risk of SUDI

The 16 papers included in the meta-synthesis are described individually in Table 5, below. From these 16 publications, 4 were related to the same study in the USA (describing different topic areas of the same dataset), giving 13 separate studies. Most (7/13) were conducted in the USA (42-51), with two from New Zealand (52, 53) and 4/13 from the UK (54-57). The studies span 19 years from 2000 – 2019. Six out thirteen (46%) studies included fathers (42, 43, 47, 49, 52, 55), though all were in the minority and none analysed their data separately. Eight papers used Thematic analysis (43, 44, 51-55, 57), five used Grounded Theory (45-47, 49, 50), two used Content Analysis (42, 48) and one used Interpretative Phenomenological Analysis (56). All papers reported themes.

Participant numbers ranged from 5-136 depending on the study design, studies with focus group data used more participants. Participants were selected mostly through healthcare settings or community-based centres. There was a wide variety in eligibility criteria, with two studies only using ethnicity (47, 52), one using education level (43), five recruiting from deprived areas (48, 49, 53, 55, 57), two using young maternal age (42, 50) and three using a combination of factors to identify those at increased risk (six papers) (44-46, 51, 54, 56). Characteristics of included qualitative papers are shown in Table 5, below.

Table 2: Characteristics of included interventions to reduce the risk of SUDI in families with children considered to be at high risk

Lead Author Year Country	*Study Design & Sample size*	*Target Population*	*Intervention*	*Study Aim*	*Mode of Delivery*	*Key Findings/ Measure of success*	*QATSDD score/%*
Infant Sleep Space & Education Programme							
Baddock, S.A. 2017 New Zealand	RCT 98 I/V 101 Control	Maori pregnant women living in low socio-economic areas	Provision of a woven flax bassinet (Wahakura) designed to provide a consistent infant sleep environment.	To compare an indigenous sleep device (Wahakura) for infants at high risk for sudden unexpected death with a bassinet, for measures of infant sleep position, head covering, breastfeeding, bed-sharing, and maternal sleep and fatigue.	Face to Face Printed material Infant sleep space Individual	No significant differences in infant risk behaviours in Wahakura compared with bassinets. Increase in sustained breastfeeding in the Wahakura group.	29/42 69.0%
Carlins, E.M. 2007 USA	Evaluation 150	Low-income families	Crib distribution & safe sleep education	Evaluate Cribs for Kids campaign; crib distribution and safe sleep education	Face to Face Printed material Infant sleep space Individual	100% reported use of the distributed crib. No SUDI deaths reported for the crib distribution families (still resident in locality).	18/42 42.9%
Young, J. Govt report – not subject to peer review 2018 Australia	Test of concept trial 158	Aboriginal & Torres Strait Islanders	Pepi-Pod programme	Pepi-Pod programme evaluation	Face to Face Printed material Infant sleep space Individual	Pepi-Pods acceptable to and used by families; improved safe sleep recommendation adherence.	25/48 52.1%
Engel, M. 2017 USA	Pre-post surveys and observation 75	Need was determined holistically by maternal infant health programme (MIHP) staff, with indicators including low-income, racial minorities, and migrant worker status.	Crib distribution & safe sleep education	Identify changes in knowledge and how many parents used the cribs provided by Crib distribution programme	Face to Face Printed material Infant sleep space Individual	99% using the distributed crib. Increased knowledge supine position (59% pre - 89% post).	27/42 64.3%

Cowan, S. Report – not subject to peer review 2015 New Zealand	Evaluation of programme implementation 3616	infants aged <2 weeks, smoke-exposed, premature or low birth weight, with local discretion for exceptions based on safety assessments of the care-giving professional	Pepi-Pod programme	To examine distribution, follow-up and user-feedback records	Face to Face Printed material Infant sleep space Individual	Maori IMR decreased. Pepi-Pods acceptable to and used by families; improved safe sleep recommendation adherence.	31/48 64.6%
Hauck, F.R. 2015 USA	Prospective cohort study 6515	(1) no crib in the home; (2) low income status (3) at least one risk factor for SIDS and sleep-related death (ethnicity, maternal smoking, pre-term or low birth weight, or sibling of a SIDS infant)	Crib distribution & safe sleep education	Evaluate Bedtime Basics for Babies campaign; crib distribution & safe sleep education	Face to Face Printed material Infant sleep space Individual	Knowledge of sleep position improved from 76% to 94%, bed-sharing decreased from 38% to 16%, 90% of parents used a crib.	32/42 76.2%
Yuill, C. Report – not subject to peer review 2017 UK	Feasibility study 79 I/V 70 Control	Young parents, parents who had smoked in pregnancy, and those known to be substance users.	Plastic baby box bed & safe sleep education	Feasibility study for RCT to introduce UK version of Pepi-Pod programme	Face to Face Printed material Infant sleep space Individual	Intervention reduced sofa co-sleeping to 6% vs 23% of controls and decreased mean bed-sharing hours to 2.6 per night compared to 6.8 for controls.	21/48 50.0%
McIntosh, C. 2018 New Zealand	RCT 101 I/V 110 Control	Maori & Pacific women	Pepi-Pod programme	Assess acceptability and effectiveness at improving SUDI protective knowledge and safe sleep practice from the Pepi-Pod programme compared to usual care	Face to Face Printed material Infant sleep space	Improvements seen in both I/V & control groups due to more than usual care provision for control group, as all participants were provided a cot.	25/42 59.5%
Salm-Ward, T.C. 2018 USA	Cohort study 208	High-risk parents (demonstrated financial need)	Crib distribution & safe sleep education	Compare parental knowledge and practices related to infant sleep before and after receipt of safe sleep educational	Face to Face Printed material Infant sleep space Group Interactive	Knowledge of recommendations on position, surface, environment, pacifier, smoking and breastfeeding increased significantly between pre & post-test and most maintained knowledge at follow-up.	24/42 57.1%

				programme and receipt of a crib			
Intensive Home Visiting or Targeted Services							
Dillon, E. 2012 UK	Service Case Study 1047	Alcohol/ substance misuse, violent criminal history, previous child not living with parent, late ante natal booking, homelessness with mental health/domestic abuse/probation, hearing impaired.	Vulnerable baby service: multi agency case planning meetings, and a public health approach.	Engage vulnerable families in the design of their support package with the aim to reduce risks of SUDI	Face to Face Interactive	Infant deaths reduced by 60% in Manchester. SUDI rate decreased from 1.8/1000 to 0.52 in 2011.	10/42 23.8%
Hutton, J.S. 2017 USA	RCT 160 I/V 122 control	Low SES mothers	Home visiting education with Baby Book	To test the efficacy of a specially designed children's book compared to brochures for safe sleep knowledge and adherence	Face to Face Printed material Individual	Safe sleep knowledge increased cross all time points for both groups. Bed-sharing was higher and exclusive crib use lower in the brochure group. Greater dialogue and emotional engagement were reported with use of the book.	30/42 71.4%
Kemp, L. 2013 Australia	RCT 111 I/V 97 Control	Vulnerable parents: one of a list of risk factors	Maternal Early Childhood Sustained Home-visiting (MECSH) Programme	To develop a theory of change for pre-natal home visiting by nurses in the context of sustained nurse home visiting programmes by exploring pre- and postnatal outcomes and the characteristics of the MECSH programme intervention	Face to Face Individual Interactive	Less instrumental deliveries; improved health & wellbeing scores; improved coping & self-efficacy in parenting in the intervention group.	30/42 71.4%
Olds, D.L. 2014 USA	RCT 458 I/V 680 Control	African American mothers living in highly disadvantaged urban neighbourhoods	Nurse-Family Partnership	All-cause maternal mortality & preventable-cause infant mortality	Face to Face Individual Interactive	Intervention group mothers less likely to die from all-causes and offspring less likely to die from preventable causes.	35/42 83.3%
Peer Educators							
Cowan, S. Report – not subject to peer review	Evaluation of a pilot study 7	Women and their partners who had successfully quit	6+1 peer education	To achieve high levels of awareness of 6+1 information in communities that	Face to Face Printed materials Individual Interactive	Link workers (parents) reported 70 6+1 conversations; total of 90 6+1 conversations reported at evaluation.	28/48 58.3%

2008 New Zealand		smoking during pregnancy		make low use of traditional health services, to achieve 50 ‘6+1’ conversations in 1 month		Hard to reach became ‘easy to reach’ by changing the communication paradigm.	
Gilchrist, A. Report – not subject to peer review 2016 UK	Evaluation of web-based peer support for young parents 55	Young parents	Little Lullaby project: raise awareness and reduce risk for SIDS in young parents	Young parents adopt and feel confident in applying the Lullaby Trust’s recommended ‘safer sleep for babies’ advice	Face to Face Digital	97.5% of young parents learned about safe sleep and SIDS risk reduction; some parents changed behaviour as a result.	30/48 62.5%
Health Education Interventions							
Ahlers-Schmidt, C.R. 2014 USA	Evaluation surveys 180	African American women	Safe sleep community baby shower	To describe participants’ knowledge and intentions regarding safe sleep following a Community Baby Shower	Face to Face Printed material Infant sleep space Group	High levels of safe sleep knowledge and stated intentions to follow safe sleep recommendations were reported by participants.	27/42 64.3%
Ahlers-Schmidt, C.R. 2019 USA	Evaluation surveys 845	Pregnant women of low socioeconomic status or with high risk of infant mortality	Safe sleep community baby shower	To evaluate outcomes of Safe Sleep Instructor-led community baby showers, which included safe sleep promotion, breastfeeding promotion and tobacco cessation education.	Face to Face Printed material Infant sleep space Group	Significant increases were observed in Baby Shower participants’ reported plans to follow the AAP Safe Sleep guidelines (all $p < 0.001$).	26/42 61.9%
Ostfeld, B.M. 2005 USA	Pre-post intervention surveys 810	Adolescents/ parents	High school education programme	Improve SIDS risk knowledge	Face to Face Group	Awareness that supine sleep position carried less risk and infant smoke exposure increased risk of SIDS improved post intervention.	14/42 33.3%
Burd, L. 2007 USA	Pre-post intervention surveys 341	Native American women	Discussion covering 9 risk factors, provision of a printed baby blanket and printed materials.	To complete a community-based efficacy study of a SIDS risk reduction methodology.	Face to Face Printed material Individual	Pre-test identified significant safe sleep knowledge deficit, higher in Native American group. Intervention improved knowledge on all nine items in both groups	24/42 57.1%
Rienks, J. 2013 USA	Telephone surveys following campaigns 1458	African Americans 18-64 yrs	3 media campaigns	Evaluate campaign effectiveness in African Americans	Digital Leaflet Posters	Exposure to 3 campaigns was successful in raising awareness of IM disparity in African Americans.	32/42 76.2%

Targeted Education Messages via Digital Media							
Carlin, R.F. 2018 USA	RCT 569 I/V 625 Control	African American mothers	Targeted and enhanced safe sleep messages	evaluate the impact of targeted messages about safe sleep and SIDS risk reduction on African American mothers decisions regarding the infant sleep environment: Sleep position	Digital	Supine position use decreased over time. Behaviour unchanged by enhanced message intervention.	30/42 71.4%
Mathews, A. 2016 USA	RCT 569 I/V 625 Control	African American mothers	Targeted and enhanced safe sleep messages	evaluate the impact of targeted messages about safe sleep and SIDS risk reduction on African American mothers decisions regarding the infant sleep environment: Soft bedding	Digital	Decrease in use of soft bedding in the intervention group: previous night 43.0% vs 52.4% in controls and over previous week 49.2% vs 59.6% in controls.	26/42 61.9%
Moon, R.Y. 2016 USA	RCT 569 I/V 625 Control	African American mothers	Targeted and enhanced safe sleep messages	evaluate the impact of targeted messages about safe sleep and SIDS risk reduction on African American mothers decisions regarding the infant sleep environment: Sleep location	Digital	Women receiving enhanced messages were no less likely to bedshare: no effect of intervention.	25/42 59.2%

Table 3: Characteristics of included interventions to improve engagement with services in families with children considered to be at high risk of significant harm through abuse or neglect

Lead Author Year Country	*Study Design Sample size*	*Intervention*	*Target population*	*Primary Outcome*	*Key findings*	*QATSDD Score / %*
Ingoldsby, E. M. 2013 USA	Quasi-experimental 2419	Flexible delivery of Nurse-Family Partnership (FNP) program, with families given more choice over content and timing of delivery of FNP at intervention sites compared to standard FNP at control sites.	Families receiving FNP-low income first-time parents	Retention in FNP program Number of home visits achieved	Lower risk of drop-out for mothers at intervention sites (HR, 0.42; 95 % CI, 0.21–0.84, p=0.015). More home visits but small treatment difference of 1.4 visits (95 % CI, 0.58–2.2), p<0.001]	36/42 86%
Folger, A. T. 2016 USA	Quasi-experimental 5707	Community- based enriched home visiting (CBE-HV) compared to standard home visiting at different locations and pre and post implementation analysis. CBE-HV worked with community stakeholders with parent support groups, material support for families in crisis, and work with families who missed appointments.	African American first-time parents with one or more of low income, being unmarried, under 18 years or incomplete antenatal care.	Retention in program Number of home visits	CBE-HV families stayed in programme for 166 days longer (461 vs 295 p<0.01) and had additional 7 home visits (24 vs 17 p=0.02) CBE-HV sites had a lower risk of attrition 69% retained at 6 months vs 58% prior to CBE-HV(p=0.03), at 12 months 55% vs 34% (p<0.01).	29/42 69%
Loman, L. 2015 USA	RCT 4538 families randomised. Engagement data from 733	Differential Response (DR) compared to traditional child protection investigation.	Families referred for Child Protection investigation considered suitable for DR	Family Engagement Index (FEI) score 0-28	Slightly higher FEI scores for DR families compared to control mean 24.0 vs 22.4 (p<0.001).	33/42 79%
Cameron, G. 2015 Canada	Quasi-experimental 261	Locally accessible child welfare offices using Differential Response (DR) compared to central child welfare offices using traditional child protection investigation.	Families referred for Child Protection Investigation to local or central offices	Feedback from parents	Parents preferred locally based DR services. 65% vs 39% (p<0.05) said they would refer a friend for support, 61% vs 41% (p<0.05) would seek help in future.	22/48 46%
Damashek, A. 2012 USA	RCT 1305	SafeCare (SC) home-treatment programme for child abuse and neglect compared to services as usual (SAU) – referral to parenting programmes, employment and social support.	Families referred for child welfare services	Families identified goals and completed goal completion scale 0-4	Small benefit of SafeCare mean goal completion score 3.5, (SD 0.9) vs SAU 3.3, (SD 1.1; t(638)=2.6, p=.01).	34/42 81%
Bolt, M. 2015	Observational evaluation 93	Evaluation of implementation of SafeCare with no comparison group.	Families referred for child welfare services	Retention in program	42% completion rate for SafeCare	20/42 48%

USA (Master's Thesis)						
Chaffin, M. 2009 USA	2x2 RCT 192	Comparison of Motivational Interviewing (MI) pre-parenting group intervention with standard pre-parenting group information; then comparison of dyadic Parent - Child Interaction Therapy (PCIT) with standard group parent training.	Parents referred following child protection investigations	Survival analysis for 12 session program.	Cumulative survival for the MI–PCIT condition was highest at 85%, 56% for MI–standard, 64% for standard–PCIT, and 64% for standard–standard.	31/42 74%
Forrester, D. 2018 England	RCT 165	Social workers trained in Motivational Interviewing (MI). Families randomised to MI trained social worker or standard social worker.	Parents following child protection referral	Working Alliance Inventory completed by parents and social workers.	No significant difference between groups	32/42 76%
Damashek, A. 2011 USA	RCT 398	Comparison of home visiting programme using both Motivational Interviewing and SafeCare (SC+) with Services as Usual (SAU) -referral to parenting programmes, employment and social support.	Families with substance abuse, mental health problems or domestic violence but excluding those known to child protection services	Enrolment with and completion of therapeutic treatment services.	80% enrolled in SC+ services vs 49% enrolment in SAU (OR 4.3 2.6-7.0 P<0.001), 50% SC+ completed programme vs 21% SAU (OR8.5 3.3-22.1, P<0.001).	33/34 79%
Silovsky, J. 2011 USA	RCT 105	Comparison of home visiting programme using both Motivational Interviewing and SafeCare (SC+) with control of community based mental health services.	Families with substance abuse, mental health problems or domestic violence but excluding those known to child protection services	Enrolment with and completion of therapeutic treatment services.	SC+ clients were significantly more likely to engage with services, 83% SC+ completed initial assessment interview vs 33% control (p<0.001), SC+ attended more treatment sessions mean 36 hours vs 8 hours (p<0.001). < 50% SC+ participants completed all 3 SafeCare modules.	36/42 86%
Morgenstern, J. 2006 USA	RCT 302	Intensive case management (ICM), managers working with clients alongside of treatment programme to remove barriers to treatment, compared to usual care (UC) of referral to treatment services and child welfare.	Substance abusing women, recruited through welfare offices	Initiation, engagement, retention, completion of drug treatment programme over 15-month period	Significantly better engagement with ICM compared to UC; 66% ICM initiated treatment vs 50% UC (p=0.0045), engagement rates 60% ICM vs 34% UC(p=0.0001). retention rates 42% ICM vs 18% UC (p=0.0001). ICM attended more treatment days, 301 vs 182 (p=0.0001). Rates for programme completion 43% ICM vs 23% UC (p=0.0001).	31/42 74%
Andrews, N. 2018	Retrospective chart review	Comprehensive programme involving addiction treatment	Substance abusing mothers	Retention in program,	Antenatally referred mothers stayed engaged in the service for	23/42 55%

Canada	160	services, parenting support, child welfare, child health and development services.		attendance at treatment sessions	a mean of 27 months vs 11 months for self-referrals, 16 months for referrals from other healthcare professionals (p<0.006). Antenatally referred mothers attended a greater number of services.	
Stover, C. 2015 USA	RCT 17	Comprehensive treatment programme for fathers with substance abuse and domestic violence, including parenting support, compared with stand-alone drug treatment services.	Fathers with substance abuse and domestic violence	Attendance at treatment sessions	no significant difference.	29/42 69%
Dakof, G. 2009 USA	Retrospective case review 80	Engaging Moms Programme (EMP), case workers helped mothers comply with court orders by focussing on improving motivation, emotional wellbeing, and parenting skills, compared to standard intensive case management in drug courts prior to start of EMP.	Court based programmed for drug abusing mothers	Court outcome data	72% of EMP mothers completed all drug court requirements compared to 38% standard treatment (p=0.002).	22/42 52%
Dakof, G. A. 2010 USA	RCT 62	Engaging Moms Programme (EMP), case workers helped mothers comply with court orders by focussing on improving motivation, emotional wellbeing, and parenting skills, compared to standard intensive case management in drug courts.	Court based programmed for drug abusing mothers	Court outcome data	No significant difference between EMP and control	31/42 74%
Bigelow, K. M. 2008 USA	RCT 19	Mobile phone enhanced planned activities training (PAT) compared to standard PAT; a home visiting intervention aimed at improving parent-child interaction.	Families with maltreatment concerns	Programme completion rates	No significant difference.	16/42 38%
Baggett, K. 2017 USA	RCT 159	Internet training programme to reduce child maltreatment focussed on play and learning to improve maternal sensitivity compared with internet training programme on general developmental awareness.	Mothers with children considered to be at high risk for child maltreatment	Number of internet sessions completed	No significant difference.	32/42 77%

Table 4: Characteristics of included qualitative studies to improve engagement with services of families with children considered to be at high risk of significant harm through abuse or neglect

Lead Author(s) *Year* *Country*	*Study Design*	*Sample Size*	*Study Aim*	*Target Population*	*Topic Guide broad categories*	*Analysis*	*QATSDD Score/ %*
Akin, B.A. 2018 USA	Qualitative interviews	10 parents	To understand parents' experiences of the supports and barriers to engagement in an Evidence Based Parenting Intervention (EBPI)	Parents who had completed Strengthening Families program, having been required to by federal drug treatment court	Participants' attitudes towards the intervention's structure and features and perceived facilitators and barriers to participation in the intervention	Thematic Analysis	28/42 (66.7%)
Altman, J.C. 2008 USA	Mixed methods – qualitative interviews, survey	36 interviews 77/155 eligible parents completed survey	How engagement and partnership unfold in child welfare practice as well as their importance to the ongoing permanency planning for children in the child welfare system	Staff from one neighbourhood-based family service centre and parents where there are significant child protection concerns	Conceptualization of engagement, its attributes, differential aspects, development, meaning, related factors, ways to promote, and perceived benefits of engagement	Spradley’s (1979) developmental research sequence (DRS).	40/48 (83.3%)
Berrick, J.D. 2011 USA	Qualitative focus groups and interviews	21 mothers, 4 fathers + 6 peer mentors	To examine perceptions and shared experiences of those receiving mentoring as well as those of the mentors themselves	Parents reunified with children who have been previously removed	Nature of the relationship with the peer mentor, nature of the services offered, strengths and weaknesses of the programme	Thematic analysis	26/42 (61.9%)
Farrell, A.F. 2012 USA	Mixed methods - qualitative interviews; Alpert and Britner's Parent Engagement Measure	41 parents	To examine client perspectives on the level and nature of their engagement in the programme and to validate further an existing measure of engagement	Families with unstable housing and CP concerns- mostly single parents, mostly low income, high proportion BAME	To elicit perceptions of engagement with the case manager and service planning: How would you describe your caseworker’s job? Do you feel involved in your child welfare case and with SHF?	Grounded theory	42/48 (87.5%)
Featherstone B. 2012 England	Qualitative questionnaire telephone interviews, face to face interviews	52 families - 18 gave feedback 19 social workers for 23 cases, 12 conf chairs for 29 cases	To evaluate an advocacy scheme for parents whose children were subject to child protection proceedings where co-operation between parents and professionals was an issue	Parents with child protection concerns	Questions in relation to engagement and perceptions in relation to outcome	Case study	8/42 (19%)

Garcia, A.R. 2018 USA	Qualitative focus groups and interviews	34 parents	(1) What inner and outer contextual factors influence access to and active engagement in TripleP, and (2) To what extent do they believe TripleP is effective in addressing children's maladaptive behaviours and promoting positive parent-child interactions?	Families referred to child welfare - 75% of children placed in kinship or foster care	Not reported	Grounded theory	40/42 (95.2%)
Gockell, A. 2008 Canada	Qualitative interviews	35 parents	To understand the active ingredients of effective interventions by learning from parents who experienced a family preservation intervention themselves	Parents enrolled in family preservation projects	Not reported	Strauss and Corbin (1990) Constant comparison method (GT)	20/42 (47.6%)
Lalayants, M. 2013 USA	Mixed methods - parental satisfaction survey, qualitative interviews	60 including parent representatives (n= 9), birthparents (n= 21), and child protective services workers and supervisors (n= 30)	To identify birthparents' satisfaction levels with parent representatives; examine perceptions of multiple stakeholders (i.e. birth parents, parent representatives, and child protective services staff) about the barriers to parental engagement; and determine factors contributing to meaningful parent engagement during child safety conferences	Families with safeguarding concerns - in child safety conferences - occur after emergency child removal	Not reported	Grounded theory	36/48 (75.0%)
Seay, K.D. 2017 USA	Qualitative focus groups	45 parents	(1) the parenting role as a motivator and inhibitor to engaging in substance abuse treatment and (2) parenting-related, agency-imposed barriers and facilitators to substance abuse treatment engagement	Parents having substance abuse treatment- mostly women	How they heard about the agency's programmes, treatment motivations, their decisions to use the pro-grams, their experiences in the programmes, their futures, and suggestions for improving the programmes.	Inductive thematic analysis	29/42 (69%)
Stahlschmidt, M.J. 2018 USA	Mixed methods - qualitative focus groups & quantitative implementation data	13 Child Welfare (CW) caseworkers 12 Parent As Teacher (PAT) workers and	Evaluation of Early Childhood Connections (ECC) programme designed to connect child welfare-involved families to an existing evidence-supported home visitation program	73 referred families who are child-welfare involved for abuse or neglect	Understanding how or if CW was currently making connections with early intervention services, identifying an appropriate intervention to address gaps, and developing an implementation	Thematic Analysis- selective coding and content analysis	24/48 (50.0%)

		early childhood education staff			strategy; identifying differences between the original implementation plan and how ECC was actually operationalized as implementation unfolded.		
Witkin, A.L. 2013 USA (PhD Thesis)	Mixed Methods- Qualitative focus groups and quantitative surveys	170 families	To evaluate the effectiveness of a community-based, child maltreatment prevention programme that emphasized parental collaboration (working as partner with agency worker) and parental empowerment (focusing on parenting strengths) in achieving successful rates of engagement and retention working with families at-risk for child maltreatment	a) pregnant women and teens from specific ethnic minority groups (African American, undocumented Latinos and Monolingual Spanish speakers and fathers)	Questions were focused on engagement and retention, services, and outcomes, yet were broad enough to allow parents to freely share their individual experience	Qualitative content analysis; Varimax factor analysis and matched paired t-tests	45/48 (93.8%)

Table 5: Characteristics of included qualitative papers on decision making for the infant sleep environment in families with children considered to be at high risk of SUDI

Lead Author *Year* *Country*	*Study Design*	*Sample Size*	*Study Aim*	*Target population*	*Topic guide broad categories*	*Analysis*	*QATSDD Score / %*
Tipene-Leach, D. 2000 New Zealand	Qualitative focus groups and interviews	26	Increase understanding of present-day Maori infant care practices in order, firstly, to inform infant health message and service delivery to Maori and, secondly, to understand the context of practices that comprise modifiable risk factors for SIDS.	Maori parents or caregivers of children under 12 months old	Infant sleep arrangement, traditional practices, best practices for baby's health and wellbeing, support available, barriers to support, worries and rewards of parenting.	Thematic Analysis	22/42 (52.4%)
Mosley, J. M. 2007 USA	Qualitative focus groups and interviews	136	To determine decision making factors for infant sleep position among low-income parents and other relatives.	Parents of children under 12 months. Education level (not specified or reported) used as proxy for income level.	Sleeping place: where, what made you choose that? What do you like about that place? Same for other children? What advice have you gotten on sleep? If you have questions about your child who do you contact? Whose opinions do you trust most? Is Dr a source of info? Role of pamphlets, public service announcements?	Thematic Analysis	30/42 (71.4%)
Miller, L. H. 2008 UK	Qualitative Interviews	16	To explore parents' understanding of the recommended cot death prevention strategies, and to discuss what they are doing in practice.	Parents of infant 0-6 months who had not previously suffered a cot death. Recruitment in disadvantaged area.	What safety measures had been carried out? What advice had they been given, how they felt about it, was it easy to follow?	Thematic Analysis	27/42 (64.3%)
Chianese, J. 2009 USA	Qualitative focus groups	28	To understand parents' motivations for bed sharing with their infants aged 1–6 months, their beliefs about safety concerns, and their attitudes about bed-sharing advice.	Primary caregivers of infants 1- 6 months, who bedshared regularly. Recruitment from inner city centre serving families in receipt of Medical Benefit.	Best experience of sleeping with baby. Decision to sleep with baby. Changes to sleep over time. Advice to give others. Concerns about sleeping with baby. Advice been given about bed-sharing. Primary care provider's role to help with concerns about bed-sharing.	Grounded theory	39/42 (92.9%)
Joyner, B. L. 2010 USA	Qualitative focus groups	83	To investigate, using qualitative methods, factors influencing African	African American mothers with infants < 6 months, whose parents were born in	Where is the best place for a baby to sleep? How do you feel about baby sleeping in a crib? How do you feel about	Grounded theory	32/42 (76.2%)

	and interviews		American parents' decisions regarding infant sleep location (room location and sleep surface).	the USA. Socio-economic status determined by: parental education, medicaid eligibility, eligible for Special Supplementation Programme for Women, Infants and Children.	baby sleeping in bed with you? What do you think about baby sleeping in own room, not your room? At what age is it ok for baby to have own room? What do you think about pillows, blankets and bumper pads? Where would you never allow baby to sleep?		
Moon, R. Y. 2010 USA	Qualitative focus groups and interviews	83	To investigate, by using qualitative methods, perceptions about sudden infant death syndrome (SIDS) in African American parents and how these influence decisions.	African American mothers with infants < 6 months, whose parents were born in the USA. Socio-economic status determined by: parental education, medicaid eligibility, eligible for Special Supplementation Programme for Women, Infants and Children.	Heard of SIDS? What do you think SIDS is? When did you first hear about SIDS? Did you know SIDS is high in AA community than any other community? Do you worry about SIDS happening to your baby? Do you know anyone who has had a baby die suddenly? What do you think causes SIDS? Do you think you can do anything to try to keep SIDS from happening? Why/why not? Do any of the SIDS recommendations have an impact on how you care for your baby?	Thematic Analysis	33/42 (78.6%)
Ajao, T. I. 2011 USA	Qualitative focus groups and interviews	83	To examine factors influencing decisions by black parents regarding use of soft bedding and sleep surfaces for their infants.	African American mothers with infants < 6 months, whose parents were born in the USA. Socio-economic status determined by: parental education, medicaid eligibility, eligible for Special Supplementation Programme for Women, Infants and Children.	Use of blankets, sleep surface firmness, bumper pad use	Thematic Analysis	32/42 (76.2%)
Yuma-Guerrero, P. J. 2013 USA	Qualitative Focus Groups	58	To gain an understanding of pregnant and parenting teenagers' child safety beliefs and practices related to leading mechanisms of injury-related death for young children.	Teenage parents enrolled at participating school, pregnant or parenting, spoke English or Spanish.	Worries, biggest threat, where does baby sleep, location, surface, anything around baby, wearing, position, has anyone talked with you about how to put your child to sleep, who, what did they tell you, do you plan to follow their advice?	Content Analysis	22/42 (52.4%)
Gaydos, L. M. 2015 USA	Qualitative Focus Groups	60	To understand how low-income, African American mothers understand and act upon safe sleep recommendations for new	African American mothers, over 18, spoke English, first time mother of infant < 6months.	Safe sleep practices, reasons for bed-sharing, reasons for prone or side position, understanding of recommendations from health workers.	Content Analysis	24/42 (57.1%)

			borns and how providers counsel these mothers.				
Herman, S. 2015 USA	Qualitative Focus Groups	73	To investigate, by using qualitative methods, beliefs among African American and American Indian families about infant safe sleep practices, barriers to acceptance of prevention recommendations, and more effective messaging strategies.	African American or American Indian mothers with babies under 2 or their 'supporters'	infant safe sleep practices, how participants placed babies for sleep, what they heard about keeping their babies safe during sleep, which safe sleep messages made sense and did not make sense, and which would work best with parents.	Grounded theory	19/42 (45.2%)
Caraballo, M. 2016 USA	Qualitative Focus Groups	43	To investigate practices, knowledge, attitudes, and beliefs regarding infant sleep among adolescent mothers, a demographic at high risk for sudden unexpected infant death, and to identify novel public health interventions targeting the particular reasons of this population.	Adolescent mothers with infants younger than 1 year, who attend high school day care centres.	knowledge, attitudes, beliefs, and current practices for safe sleep, information sources, factors motivating decision making, opinions on the most effective mode of delivery of educational messaging to young mothers.	Grounded theory	22/42 (52.4%)
Crane, D 2016 UK	Qualitative Interviews	46	to discover how white British and Pakistani mothers in Bradford recall, understand and interpret SIDS-reduction guidance, and to explore whether and how they implement this guidance in caring for their infants.	Mothers residing in socio-economically deprived inner-city areas, with infants aged 8-12 weeks.	Feeding, Baby's night sleep (surface, room, position, swaddling, temp), day-time naps, day care, temperature, dummy use, bath time, daily interactions, household arrangements, cultural norms, health information.	Thematic Analysis	30/42 (71.4%)
Joyner, B. L. 2016 USA	Qualitative focus groups and interviews	83	To investigate African American parental reasons for pacifier use or non-use, and whether knowledge of the association with decreased SIDS risk changes decisions about pacifier use.	African American mothers with infants < 6 months, whose parents were born in the USA. Socio-economic status determined by: parental education, medicaid eligibility, eligible for Special Supplementation Programme for Women, Infants and Children.	How do you feel about pacifiers? Should there be an age requirement for pacifiers? When did your baby start using a pacifier? Has anyone ever talked to you about using a pacifier? What are the advantages to using a pacifier? What are the disadvantages to using a pacifier? If you were against pacifiers and were told that using a	Grounded theory	34/42 (81.0%)

					pacifier decreased the chances of your baby dying from SIDS, would that change your mind?		
Clarke, J.A. 2016 New Zealand (Master's Thesis)	Qualitative Interviews	13	To explore how maternal values, safe sleep knowledge and practical realities influence decision making in the night-time care of infants in one suburb in Christchurch, New Zealand.	Mothers living in economically deprived areas with babies under 6 months old.	Night-time care, partner involvement, challenges, advice, sources, trust, conflicting information, mothering, safety and sleep, risk taking (self and others).	Thematic Analysis	32/42 (76.2%)
Pease, A. 2017 UK	Qualitative Interviews	20	To understand why some mothers in the UK don't follow the recommended SIDS advice, in particular mothers who are more at risk of suffering a SIDS tragedy.	Mothers with three or more from: maternal age <26, three or more children, smoking during pregnancy, IMD score in the most deprived quintile.	infant sleep position, co-sleeping, smoking, dummy use, feeding and disrupted routines.	Thematic Analysis	28/42 (66.7%)
Ellis, C 2019 UK (PhD Thesis)	Qualitative Interviews	5	To gain an understanding about the lived experience of young first-time mothers identified as being at increased risk for experiencing SUDI, their understanding of safe sleep practices, what factors influence their decision-making and behaviour in relation to their infant's sleep environment, and whether infant-care practices change over time.	White British pregnant women for whom this was their first child, were aged 16 (15 years and 12 months)to 21 (21years and 12 months) years old, and presented with at least one of the following factors: smoking; misuse of drugs or alcohol (in excess of 2 units/day in a given week (DH, 2016:6); unemployment or low income; reported housing issues (rented, overcrowding, homelessness/ sofa surfing).	What is the lived experience of a young mother? What do mothers' understand about what constitutes safe sleep? What influences decision-making around infant-care?	Interpretative Phenomenological Analysis (IPA)	42/42 (100.0%)

4.4. Synthesis of Results

4.4.1. *Interventions to reduce the risk of SUDI in families with children considered to be at risk*

What safer sleep interventions have been tested with families with children considered to be at risk for SUDI and what can these tell us about what works to reduce the risk and embed safer sleep practices for this group?

From the 23 included papers, five types of intervention were identified:

- Infant sleep space and safer sleep education programmes – 9 papers (23-25, 32-34, 36, 39, 41)
- Intensive or targeted home visiting services – 4 papers (26, 29, 37, 40)
- Peer educators/ ambassadors – 2 papers (35, 38)
- Health Education / Raising Awareness Interventions – 5 papers (19-21, 30, 31)
- Targeted health education messages using digital media – 3 papers (22, 27, 28)

Infant sleep space +/- safer sleep education programmes

Nine papers investigated the provision of a safe infant sleep space (crib, Pepi-Pod, Wahakura or plastic box baby bed) (34) or combined with the delivery of a safer sleep education programme (23-25, 32, 33, 36, 39, 41). Studies were carried out in New Zealand, USA, UK and Scotland. These studies aimed to understand the usage and acceptability of the provided sleep space by the parents, provide a safer sleep space for the infant and improve knowledge and application of the safer sleep recommendations relevant to the country of study. Outcome measures included use and acceptability of the sleep space, reduction in parental bed-sharing, particularly with parents that smoked, improved rates of breastfeeding, improved quality of maternal sleep and Cowan, Carlins and Collins, and Young (23, 34, 41) reported a reduction in the infant mortality (IM) rate in the areas that adopted the intervention, however no studies made causal associations. New Zealand saw a reduction in post perinatal infant mortality of 29% in the general population since the introduction of the Pepi-Pod programme in 2009 (58) and the report attributes this reduction to the wider, co-ordinated safer sleep public health strategy.

Intervention: Provision of infant sleep device

Wahakura is a traditionally woven flax basket baby bed and a ***Pepi-Pod*** is a polypropylene storage box with a close-fitting foam mattress, mattress protector and culturally themed bedding. Both provide a safe infant sleep space that can be brought into the parental bed to reduce the risks of direct infant-adult bed-sharing situations. The infant sleep device described in Yuill (39) is similar to the Pepi-Pod but is referred to in their study as the 'plastic baby box bed'.

Baddock et al. (33) compared the use of the Wahakura with bassinet use in a randomised trial with 200 mainly Maori women. Questionnaires were completed at 1, 3 and 6 post-natal months recording self-report outcomes for infant sleep position, head covering, breastfeeding, bed-sharing, maternal sleep quality and fatigue. The study found no significant differences between the use of the bassinet with the Wahakura, specifically there was no increase in unsafe sleep scenarios with use of the Wahakura, however, mothers using the Wahakura reported a significant increase in breastfeeding at 6 months. The study concluded that the Wahakura offered a safe alternative to infant-adult bed-sharing, with the advantage of increasing breastfeeding.

Intervention: Pepi-Pod programme

Originating in New Zealand and aiming to reduce the SIDS rate in the Maori population, the Pepi-Pod programme involves the provision of a safe infant sleep space and a SIDS risk reduction education session delivered face to face by the provider. A picture card and checklist guide intervention fidelity and prompt discussion on: how babies get their oxygen, importance of supine positioning and why, who are the more vulnerable infants and why, what are the more vulnerable sleep locations, how infants breathe and can suffocate, safety features of the sleep device, how to make it up, and its safe placement and use (34). Key safer sleep messages are attached to or embossed on the base of the Pepi-Pod to reinforce the messages, an information card is included and 'infant care' labels are sewn into the bedding. Parents on the programme are encouraged to pass on the Pepi-Pod once they have finished using it and share the SIDS risk reduction messages with the new owners.

Cowan (34) Reported on three years of programme implementation. Data were collected at distribution, at 2-3 weeks and a sample of users after 8-10 weeks. The aim of study was to ascertain acceptability of the sleep space, improvement in infant safety, adherence to safer sleep recommendations, impact on bed-sharing and whether recipients shared safer sleep information across their networks. The study reported that the programme was applied consistently, Pepi-Pods were accepted, used and liked by parents and were portable. Follow up demonstrated high uptake of safer sleep (supine & own bed) and safe baby (immunisation, breastfeeding, gentle handling, being smoke-free or receiving support to quit, and registration with health services) outcomes. 80% of recipients reported sharing safer sleep messages across their networks, producing a mean of 6.2 conversations per recipient. An important measure reported was the reduction in the IMR for Maori infants during the period of the intervention from 4.4 in 2012 to 3.0 per 1,000 live births, in 2014. While this reduction cannot be specifically attributed, the authors suggest that the intensive and targeted intervention contributed to this fall.

McIntosh et al. (36) The study aimed to measure the impact of the Pepi-Pod programme on SUDI protective knowledge, infant care practices and the acceptability of using the Pepi-Pod for Maori and Pacific Island parents in New Zealand. Questionnaires were completed at baseline, and home interviews were conducted at 2 and 4 post-natal months. At commencement of the study, 25% parents did not have a cot for the infant and almost a third of mothers planned to bed-share from birth. Although participants were randomised, both groups were offered a portable infant cot and some control families were also given enhanced SIDS messages (where unsafe sleep was seen or disclosed). Almost all of the participants in both arms of the trial accepted the offer of the portable infant cot and so it is difficult to assess the effectiveness of the Pepi-Pod in this study. Through the questionnaire data Pepi-Pods were found to be acceptable infant sleep spaces and were regularly used by 46% of parents at 2 months and 16% at 4 months follow up. Little difference in knowledge and behaviour was observed between groups, and bed-sharing 'sometimes' or 'usually' during the past week was reported in 81% and 75% of the intervention and control group, respectively.

Young et al. (41) This evaluation reports on the impact and feasibility of extending the Pepi-Pod programme introduced into Queensland, Australia. In addition to the New Zealand version, was an eLearning programme launched to underpin the Queensland Health Safe Infant Sleeping policy, which can be accessed by staff delivering the Pepi-Pod programme. 600 Pepi-Pods were distributed and data on 123 families were evaluated. 83 families reported using the Pepi-Pod for some, most or all sleeps. Infants placed into the Pepi-Pod less frequently were likely to be older than 8 weeks. Recipients rated five aspects of care on a scale. Outcomes measured were maternal sleep, 84.5% recipients reported improved quality of sleep using the Pepi-Pod; breastfeeding, 60.2% reported a positive impact on feeding; convenience, 84.5% parents reported ease and convenience of the Pepi-Pod; safety, 87.3% identified Pepi-Pod as safe; and settling, 71.3% reported the Pepi-Pod aided settling their infant. Results also identified a reduced risk of SUDI in families from the interaction between smoking and bed-sharing, with 57% of smoking families using the Pepi-Pod. Early IM data for Queensland demonstrates a reduction in the IMR, however, no specific data directly mapping the IMR to the intervention areas is available yet.

Yuill et al. (39) A feasibility study across 2 sites in the UK of an infant sleep space (plastic baby box bed, (modelled on the New Zealand Pepi-Pod) and an educational intervention were developed and tested in this study. The educational materials were well received as practical and realistic. There were no details about the content of these materials in the paper. The plastic baby box bed for use in the parental bed, received mixed reviews, with parents who liked and used it reporting favourably, but others found use more challenging due to design. Generally, parents liked the concept, and would recommend its use, even those choosing not to use the baby box bed. Reported results included improvement in less exposure to some hazardous sleep environments, sofa sharing at 1 month (6% vs 23% control) and co-sleeping with overly tired parents (extreme fatigue at 2 months), at 13% vs 27% in controls. Combined findings from the 2 sites suggests overall less co-sleeping in the intervention group at 2 months (mean 2.6 hours/night compared to a mean 6.8 in controls), however this was not significant. Qualitative data indicated that the baby box beds were used for infant sleep in different locations around the home for day-time sleeps, keeping the infant in close proximity, which is associated with reduced risk for SUDI and for out of home sleeps. Face to face delivery of the intervention was received more positively when delivered at home compared to the antenatal hospital visit.

Carlins and Collins (23) The Cribs for Kids campaign aimed to reduce the risk of SIDS and accidental suffocation and provide education and a safer sleep environment for infants. Educational material outlining the risks for SIDS is included with the crib and some communities set up face to face or group education sessions. 320 cribs were distributed in the first year of the programme and 105 families were surveyed to test parental knowledge of SIDS risk and efficacy of the programme. The results identified that although all participants claimed to have read the educational information, 50% could not explain SIDS; 34% had breastfed for some time, although no specific detail on breastfeeding was reported; 100% had attended all well baby checks and reported they were using the provided crib; 65% placed their infant supine to sleep and 38% did not have a cot and would have bedshared had the crib not been provided. No SIDS deaths were recorded for any of the recipients on the crib programme, however the number of families in the evaluation was small. The evaluation stated that the SIDS death rate fell by 63% between 1992-2003 which coincides with the launch of the US ‘Back to Sleep’ campaign in 1994 and was associated with an immediate fall in SIDS rates. While these data provide a snapshot for this evaluation, there was no baseline data or comparison with local or national statistics for context.

Hauck et al. (25) Evaluated the Bedtime Basics for Babies programme – the provision of a crib, safer sleep educational material and a 'Safe Sleep Kit' containing a pacifier and wearable blanket, recommended to reduce the risk of SIDS. The aim of the evaluation was to describe parental knowledge and practices of infant sleep position, bed-sharing, pacifier use and feeding method before and after receipt of the crib. Surveys were completed at the time of crib receipt (4,786 cribs distributed: 3,303 antenatal, 1,483 postnatal); and 1,729 parents completed a follow up survey at 1-3 months after crib receipt. Parental knowledge of sleep position increased from 76% antenatally to 94% after crib receipt; bed-sharing decreased from 38% postnatally to 16%, and crib use increased from 51% postnatally to 90% after receipt of the crib. No effect of the intervention was observed on increasing breastfeeding or pacifier use.

Engel et al. (24) Cribs and risk reduction education were delivered to 75 parents. The purpose of this study was to identify how many parents used the cribs provided. No explanation of the educational intervention is provided but results report the pre-post-test assessment of parental knowledge and a home visit to evaluate the infant sleep environment. Self-report parental knowledge increased significantly between pre and post-test scores: 89% affirmed supine sleep position, 91% removed soft and unsafe objects from the crib, however, 44% continued to bed-share. 99% of parents reported they were using a crib at the home visit, with 93% using the provided crib and 89% had no unsafe items in the crib. Engel concluded that parents provided with a crib as part of a safe seep strategy, do use them and are able to maintain a safer sleep environment for their infants.

Salm Ward et al. (32) This study aimed to compare parental knowledge and practices related to infant sleep before and after receipt of a safer sleep educational programme and receipt of a crib. Surveys were conducted pre and post educational group session, and a follow up telephone survey 10 weeks after the programme or the infant's birth. Educational programme content was informed by the Health Belief Model (59, 60) to support engagement with the content and support application in practice. Education sessions were informal and conversational to facilitate participant engagement. The fidelity of programme delivery was considered. Results between pre and post-test scores increased significantly for all items tested: sleep position, separate surface in parent's room, no soft items, smoke exposure, breastfeeding, pacifier use, and flat firm surface. No significant difference was recorded for 'overheating increases risk'. No differences were found between post-test and follow up at 10 weeks, suggesting that knowledge was retained, except for 2 items – 'smoking increases risk', and 'pacifier use reduces risk', where knowledge decreased over time. Intentions expressed between pre and post test scores suggests parental behaviour intentions changed to improve safety in sleep position, no items in crib and infant's own bed. However, intention does not always equate with practice; it is therefore, difficult to identify actual outcomes on pre – post-test parent report of intention without more robust methods of testing this.

Intensive or targeted home visiting services

Kemp et al. (40) Sustained pre & post-natal home visiting programme: a process evaluation of what worked in a multi-modal intervention. Intervention content included the importance of the early years, children's health and development, types of support parents need, parent- infant interaction and holistic, ecological approaches to supporting families to achieve the best outcomes for their children. It incorporated evidence-based elements and frameworks for service delivery shown to reduce the impact of biological, social, and environmental factors predisposing infants and children to ill health and reducing their life potential. The intervention was delivered by a specialist nurse beginning in the antenatal period continuing until the child's 2nd birthday. Mothers in the intervention group reported their general health and wellbeing to be significantly better at 4-6 weeks post-partum than controls; they experienced a higher rate of normal deliveries, although this was not significant; a significantly higher proportion of the intervention group could identify two or more measures to reduce the risk of SIDS compared to controls, however, no significant differences were observed between groups at 4 weeks for breastfeeding rates and the rates for both groups were significantly lower than reported national rates.

Olds et al. (29) Nurse Family Partnership (USA) is an intensive home visiting programme, enrolling disadvantaged pregnant women in the antenatal period with intensive home visiting continuing until the child's 2nd birthday. The aims of the programme are 1. Improving outcomes of pregnancy and prenatal health, 2. Improving children's health and development by supporting mothers to provide competent care and 3. Improve women's health, self-care, family planning, to complete their education and find employment. This study reported on 20 year follow up data, using all-cause mortality in mothers and preventable-cause mortality in children as main outcome measures. Women in the intervention group were less likely to have died and their children were much less likely to die of preventable causes such as SIDS, unintentional injuries and homicide. However, this was a relatively small sample from which to make inferences about mortality, therefore conclusions should be treated with caution.

Dillon (37) The Vulnerable Baby Service is a targeted multi-disciplinary/agency approach based in Manchester, UK. This paper was a short 'digest' outlining the intervention rather than a research paper and as such, obtained a QATSSD score of 10. The intervention aims to engage vulnerable families in the design of their support package with the aim to reduce risks of SUDI. The intervention facilitates multi-agency case planning meetings for vulnerable families and was expanded to include a wider public health social marketing campaign to reduce risk behaviours for all infants born in Manchester. Principals of the service were to: intervene early; provide a framework for effective multi-agency working; effective information sharing; consider holistic needs of the family; identify family needs and co-ordinate support to improve outcomes. Since the start of the service in 2003, the infant death rate in Manchester has declined by 60% and no SUDI have been reported in the intervention group, however, no causal association is identified in the paper. Attendance at appointments improved, disclosure of domestic abuse increased, and 86% of fathers continue to be involved in families. Organisational benefits were also observed: increased staff engagement to reduce SUDI, attend SUDI training and updates, consistent workforce approach to delivering safer sleep advice, and effective use of administrative staff to release professionals for clinical work. The service is being expanded to include other vulnerable groups of children, including birth to four and a half year olds at risk of neglect.

Hutton et al. (26) conducted an RCT to test the efficacy of a specially designed children's book compared to brochures for safer sleep knowledge and adherence. Home visitors provided safer sleep teaching and assessments during 3 visits: third trimester, 1 week old, and 2 months old, exclusively using the children's book or brochures incorporating the American Academy of Pediatrics' safer sleep recommendations. Outcomes were safer sleep knowledge, adherence to recommendations, and usefulness of materials. Safer sleep knowledge improved across all time points in both groups, but bed-sharing was higher and exclusive crib use lower in the brochure group. Mothers and home visitors reported usefulness with both book and brochure, however, home visitors reported greater dialogue with the book, and mothers in the intervention group reported more book sharing with their infant. Hutton concluded that while both media were useful in improving safer sleep knowledge in low SES mothers, exclusive crib use and reduced bed-sharing was greater in the intervention group which was attributed to the enhanced dialogue and emotional engagement with the book content. Benefits of the book were the interactive delivery, mothers commented information was 'just right' and 'related to their baby', and 81% of the intervention group were reading the book with their infant at 2 months. Emotional engagement with the book content might support the translation of knowledge into behaviour. Benefits of access to the home: provided an ecological view of how safer sleep knowledge may be assimilated and translated into adherence.

Peer Educators

Cowan and Pease (35) The *6+1* project was an infant health promotion activity that aimed to support link workers (parents) from the community to have focused discussions, supported by a baby book resource, with family and friends on key health topics: a smoke-free pregnancy, back sleeping, clear face, smoke-free air, a safe place to sleep, breastfeeding, and reading with babies. The overall goal was to achieve high levels of awareness of *6+1* information in communities that make low use of traditional health services. The target of 50 *6+1* discussions to have occurred in a four-week period was exceeded, with 91 *6+1* discussions reported. Link worker experiences were very positive, reporting increased levels of confidence and changes to their own parenting based on what they had learnt. The baby book supported and structured conversations and was valued. Information was received well by friends and family as the link workers were a trusted source. There was consideration of including a 'gentle handling' message into the book to address concerns about abuse and neglect, which would be of benefit in relation to the requirements of reaching populations relevant to this SUDI study. This intervention provides an easily scalable reach for safer sleep messages into traditionally 'hard to reach' communities. Concerns with this method of intervention was the loss of control and fidelity of information being shared by link workers, and difficulties in recruiting men as link workers.

Gilchrist (38) Little Lullaby works with young people and professionals to raise awareness and reduce risks of SIDS based on peer education and support. Gilchrist evaluated the Little Lullaby project which comprises a website and peer educators (Ambassadors) trained to deliver safer sleep advice. The service is delivered via a website and face to face talks and workshops. 19 young people gained a BTEC in peer education, 77 talks had been delivered and 54 were delivered by Ambassadors. Post talk evaluations indicate safer sleep messages are being understood and applied by young parents, 97.5% reported they had learnt something new about safer sleep and SIDS and 36.7% stated they would change parenting practice as a result of the session. The Ambassadors report gaining knowledge and confidence which encourages them back to education and employment. Benefits of the intervention: effective model for engaging and empowering young parents, and website provides useful resources, information and advice. Currently the Ambassadors are London-centric and Little Lullaby has a relatively low profile among health professionals.

Health Education / Awareness Raising / Campaigns

Ostfeld et al. (30) An interactive and culturally sensitive education programme was developed for high school adolescents in USA to address health risks associated with smoke exposure and non-supine infant sleep. Pre and post-test of knowledge of the intervention group was compared with a control group of same grade students and a convenience sample of parents. Intervention students were more likely to identify smoke exposure for the infant as a risk rather than antenatal exposure, and could recognise that supine sleep position carried the lowest risk for SIDS. This knowledge was noted to endure when re-tested 8 months later. Intervention group students also exceeded SIDS knowledge at baseline in the parent's group.

Burd et al. (21) Aimed to complete an efficacy study of a SIDS risk reduction educational intervention. Home visit vs hospital-based educational intervention was delivered by hospital nurses or home visiting staff, where nine risk factors were discussed, the rationale for changes in infant care practices to reduce or eliminate the risk factor were explained and questions were encouraged. Paired pre-post-tests assessed knowledge. Pre-tests found substantial knowledge deficits about SIDS risk factors in both groups, with Native American women demonstrating the greatest deficit. Post-test results for the nine risk factors ranged from 5% to 74%. Improvements were observed on knowledge for smoking (5%), smoke exposure (9%), alcohol use (7%), infant sleep position (8%), and infant sleep environment (60%). Participants from both groups demonstrated nearly equivalent rates of learning for all nine of the risk concepts. Of interest, many of the families already had young children, therefore the expectation would be that parents already had some knowledge regarding recommended safer sleep practices, but this was not the case.

Ahlers-Schmidt et al. (19) Evaluated safer sleep community baby showers (parties for pregnant women) for African American women, designed to increase knowledge and practice of safer sleep advice. The programme organised baby showers at which participants were given portable cots along with educational group sessions designed to promote social cohesion and information sharing. 180 people took part, with most completing the evaluation forms after the session. While knowledge of safe sleep and intentions for safe infant care were high, no baseline measure means that changes in knowledge or intentions due to the intervention could not be assessed. In a later study with pregnant women of low socioeconomic status (20), Ahlers-Schmidt et al conducted paired pre-post-test surveys of knowledge, confidence and intentions to follow safer sleep recommendations. Significant increases were observed in participants' reported plans to follow the AAP Safer sleep guidelines (all $p < 0.001$), likelihood to breastfeed ($p < 0.001$), confidence in ability to breastfeed for more than 6 months ($p < 0.001$), knowledge of local breastfeeding support resources ($p < 0.001$), knowledge of ways to avoid second-hand smoke exposure ($p < 0.001$) and knowledge of local tobacco cessation services ($p = 0.004$). However, these are parental self-reported intentions, not a reflection of actual infant-care practice. 86.4% mothers reported their infant would have slept in an alternative potentially hazardous sleep space had they not received the cribs, including adult beds (n = 55), car seats and swings (n = 15). The baby showers promoted the American Academy of Pediatrics 'ABC' message for safer infant sleep, which states that the infant should sleep alone at all times. While the authors of this paper have included the adult bed as a hazardous sleep environment, other studies have identified that bed-sharing per se does not increase risk for SIDS (61). Bed-sharing in certain circumstances, for example, when the parent is a smoker, has consumed alcohol or drugs, or where the infant is pre-term or of low birth weight, are factors which increase the risk of SIDS in the bed-sharing context. Studies that assume a risk of bed-sharing in all circumstances lose the ability to measure this important detail and miss opportunities to understand how their intervention may impact on hazardous bed-sharing.

Reinks and Oliva (31) Evaluated three media campaigns to raise awareness of IM disparity in black infants. Campaign themes: 1. infant mortality disparities, 2. proper infant sleep position, and 3. taking action to reduce disparities. Media to carry messages included bus and radio ads, and posters and cards distributed at clinics, day care, agency waiting rooms, and community organisations. Telephone surveys of African Americans aged 18-64 were conducted. 62% report some exposure to Campaign 1, 48.5% to Campaign 2, and 48.9% to Campaign 3. Increased awareness of disparity was significant ($p < .0005$), although there was no overall significant increase in knowledge about proper sleep position, and respondents who report any exposure to this campaign are more likely to know about sleep position ($p < .0001$). Reinks concluded that social marketing is an effective tool to increase disparity awareness, especially among groups disproportionately affected by the disparity.

Targeted health education messages using digital media

Matthews et al., Moon et al. and Carlin et al. (22, 27, 28) used data from the same RCT. The aim of the study was to evaluate the impact of targeted messages about safe sleep and SIDS risk reduction on African American mothers' decisions regarding infant sleep environment. Controls were sent standard messages emphasising recommended sleep practices including avoidance of bed-sharing, while the intervention group received enhanced messages to include suffocation prevention. Interviews were conducted at 2-3 weeks, 2-3 months and 5-6 months after the infant's birth. Mathews examined the data on soft bedding, Moon examined sleep location and Carlin reported on sleep position.

Matthews found a decrease in the use of soft bedding in the intervention group between first and final interviews; a reduction in use of soft bedding in the previous week of 30%, and 26% the previous night. The use of soft bedding was less if maternal 'belief' was that soft bedding increased the risk of suffocation or SIDS; however, mothers with high self-efficacy in their ability to protect their infant were more likely to use soft bedding; belief therefore, affected behaviour. Mothers who bed-shared were more likely to use soft bedding, with maternal belief in 'vigilance' as protective. Moon et al. examined the impact of enhanced messaging on sleep location and found no change in maternal bed-sharing behaviour in the intervention group and observed a gradual increase in bed-sharing activity over time in both groups despite families being in trial conditions that were directly advising the opposite. Carlin et al. reported that supine sleep position decreased over time in both groups; at 2-3 weeks 95.9% of mothers were placing their infant supine which decreased to 79.9% at 5-6 months. However, parental knowledge of the recommended sleep position was high, commonly cited reasons for using another position was fear of suffocation, choking and infant preference. Some influence was noted on maternal selection of sleep position, if nurses had discussed sleep position, mothers were more likely to select the supine position, if discussion was with the father, they were more likely to select prone; however, over time, the opinion of maternal friends became much more significant on influencing choice of sleep position. Carlin concluded there was no impact from the enhanced messaging intervention on infant sleep position.

Conclusions

The wide variety of interventions and study designs preclude any meta-analysis. Study quality was generally high but with some variation. Robust conclusions about the effectiveness of interventions in this context are not possible, however we have summarised our broad categories of interventions into two groups: potentially effective and those requiring further research (where improvements, no or negligible improvement, or the potential to effect change, were reported across a number of safer sleep outcomes).

Potentially Effective: ***Infant sleep space and safer sleep education programmes*** appeared to have the greatest impact on parental behaviour in terms of provision and use of a safer sleep space for the infant, whether a cot or in-bed sleep device, high numbers of parents reported use. Where coupled with an educational intervention, parental safer sleep knowledge was also reported as significantly improved; however, these findings were based on pre-post-test self-report data from parents. ***Intensive or targeted home visiting services*** also appear to improve maternal and infant health and wellbeing outcomes for families with vulnerable characteristics and might be more likely to influence behaviour change in parents over time. The success of such interventions may well be based on the long-term approach, improving parent-provider relationships, building trust and taking account of the changing circumstances for parents and infants. Services that are embedded within 'usual service provision', begin during the antenatal period and continue through the postnatal period, and have their foundation in a clear theoretical framework, were characteristics identified in the interventions that reported successful outcomes. ***Social media campaigns*** did provide evidence of efficacy and improved knowledge, however, as has been noted from the literature, effective interventions cannot solely rely on the provision of information, and the acquiring of knowledge, to effect behaviour change.

More Research Required: Targeted health education messages using ***digital media*** reported issues with engagement and were less effective in encouraging behaviour change in parents. Ways to improve the effectiveness of non-face to face interventions may be of use since these types of interventions are scalable and low cost. Interventions that used a ***peer educator approach*** reported increased 'reach' of safer sleep messages into the social networks of vulnerable groups. While there was good evidence of link worker conversations occurring, and reported learning about safer sleep, there was no evidence of application or behaviour change in parents as a result of those conversations, nor was there evidence of the content/ fidelity of the information shared. To assess the efficacy of such interventions requires further research into the impact on actual infant care practices. Five ***Health education interventions*** also provided evidence of high school student and parental knowledge improvement across a number of safer sleep outcomes, and as such, could be effective. Depending on the intervention, research would be required to understand the relevance and appropriateness for delivery to the UK target population. These types of intervention also need to consider measuring actual practice rather than knowledge and intention.

Seven out of 23 intervention papers solely used ethnicity as a marker of risk for SUDI (19, 21, 22, 27, 28, 36, 41), these studies are relevant where characteristics or behaviour that increases risk for SUDI in the UK population are described. While parental motivations for certain behaviours may be culturally different, the principal of exhibiting that behaviour increasing risk for SUDI should be explored when considering potential application to the UK setting.

To facilitate review of the characteristics for each intervention, the matrix has been compiled below (Table 6) and arranged by highest number of characteristics first. Some papers did not explain the intervention in detail or identify specific elements to facilitate reporting of individual intervention characteristics, for example Dillon's (37) Vulnerable Baby service components probably contributed to the fall in IMR, however specific knowledge and behaviour change in parents was not reported. Interventions that reported success and appeared to work, have a number of identifiable characteristics: they are personalised, culturally sensitive, enabling, empowering, relationship building, interactive, accepting of parental perspective, non-judgemental and are delivered over time.

Table 6: Intervention Characteristics Matrix

	Sleep device	Education	SS knowledge improvement	Behaviour change element	Home visits	Interactive	Parent perspective	Empowering	Digital	Peer educator	Group	Intervention reported successful
Gilchrist 2016		•	•	•		•	•	•	•	•	•	•
Cowan 2008		•	•	•		•	•	•		•		•
Young 2018	•	•	•	•	•	•	•					•
Cowan 2015	•	•	•	•	•	•	•					•
McIntosh 2018	•	•	•	•	•	•	•					•
Salm-Ward 2018	•	•			•	•	•				•	•
Kemp 2013		•		•	•	•	•	•				•
Ahlers-Schmidt 2019	•	•	•	•		•					•	•
Ahlers-Schmidt 2014	•	•		•		•					•	•
Hutton 2017		•		•	•	•	•					•
Hauck 2015	•	•	•	•	•							•
Dillon 2012		•			•	•	•	•				•
Burd 2007		•	•		•	•	•					•
Olds 2014		•			•	•		•				•
Ostfeld 2005		•	•			•					•	•
Mathews 2016		•		•					•			•
Baddock 2017	•			•								•
Engel 2017	•	•	•	•								•
Rienks 2013		•	•									•
Carlins 2007	•											•
Yuill 2017	•	•	•	•	•							
Moon 2016		•							•			
Carlin 2018		•							•			

4.4.2. *Interventions to improve engagement with services in* families with children *considered to be at high risk of significant harm through abuse or neglect*

What can interventions to improve engagement between families with children considered to be at high risk of significant harm through abuse or neglect and support services tell us about improving uptake of effective safer sleep interventions?

Quantitative Engagement Papers

Seven broad categories of interventions to improve engagement were identified:

1. Home Visiting Programmes
2. Differential Response in Child Protection Services
3. SafeCare
4. Motivational Interviewing
5. Motivational Interviewing combined with SafeCare
6. Comprehensive substance misuse treatment programmes
7. Technology assisted interventions

Home Visiting Programmes

Two studies looked at interventions to improve existing home visiting programmes. The Nurse-Family Partnership (NFP) (62) is an evidence- based home visiting programme for low-income, first time parents; it has been widely used in the USA and has also been adopted more recently in some areas of England. The programme involves pre and post-natal home visits by nurses with the aim of improving pregnancy outcomes, child health and development and families' economic self-sufficiency. There are 64 scheduled visits, following manualised guidelines, between antenatal registration and the child's second birthday. NFP was originally designed as a research intervention has been used in clinical practice since 1997, although clinical use is associated with higher drop-out rates; this is postulated to be due to the inflexibility of the program.

Ingoldsby, et al. (63) attempted to address this with a quasi-experimental study. At six intervention sites, nurses gave families greater control over the content and timing of delivery of the program; retention rates were compared with 11 control sites that continued the NFP as usual. Follow-up data on 2419 participants for the first 10 months of NFP for intervention and control sites before and after implementation of the intervention were obtained. There was a lower risk of drop-out for mothers at the intervention sites (HR, 0.42; 95 % CI, 0.21–0.84, p=0.015) compared to control, and they received more home visits leading to a significant but small treatment difference [increase of 1.4 visits (95 % CI, 0.58–2.2), p<0.001]. This is a small effect size, particularly given that the NFP standard schedule is for 13 home visits in this period, with the intervention group actually receiving a mean of 8.2 visits. The study does not address longer-term drop-out rates, and at best shows only a very modest benefit, in low-income first-time parents. The effects may be less for families with children considered to be at high risk of significant harm through abuse or neglect.

Folger, et al. (64) studied the impact of enhanced community input into a home visiting programme (HVP) using a quasi-experimental comparison. Eligible families for HVP were African American first-time parents with one or more of low income, being unmarried, under 18 years or incomplete antenatal care. High-risk communities were targeted for intervention, community- based enriched home visiting (CBE-

HV); this involved working with community stakeholders such as faith or neighbourhood groups, meeting regularly to inform and support HVP. Community partners promoted HVP and actively recruited families than relying on hospital referrals. Community services held parent support groups, aiming to supplement and support HVP, and provided material support to families in crisis to incentivise participation. Local community HVP coordinators were appointed to work with families who missed repeated appointments. Post-implementation CBE-HV families (n=267) were compared with similarly high-risk families (n=1924) outside of the intervention areas receiving standard HVP, CBE-HV families stayed in programme for 166 days longer than comparison (461 vs 295 p<0.01) and had 7 additional home visits (24 vs 17 p=0.02). A temporal comparison of attrition in families from the same areas prior to (n=1592) and post implementation (n=1924) of CBE-HV showed that CBE-HV had a lower risk of attrition with 69% retained in programme at 6 months post-implementation compared 58% prior (p=0.03), at 12 months this was 55% post implantation and 34% prior (p<0.01). This study shows a significant benefit of using communities to support engagement with HVP, however the children in these families, while living in circumstances of high socio-economic deprivation, were not shown to be at high risk of significant harm through abuse or neglect.

Differential Response in Child Protection Services

Child Welfare practice in the USA has considered Differential Response (DR) to child safeguarding assessments. Traditional USA child protection investigations have been based on substantiating allegations of abuse or neglect to support criminal proceedings and child removal. In DR, only the most severe child protection referrals follow a traditional approach, with more supportive approaches used in other cases. Safety plans are developed with families, these consider the allegations as well as other needs, supports and strengths in families. There is no attempt to formally prove maltreatment, and support is offered regardless of whether allegations are substantiated.

Loman and Siegel (65) conducted a RCT of DR in Ohio, USA. Child protection referrals were screened on receipt and those eligible for a Family Assessment (FA) using DR methods, were randomised to either FA (n=2291) or traditional child protection investigations as a control (n=2247). Feedback surveys were obtained from a sample of 330 FA families and 403 controls, using a Family Engagement Index (FEI) with a score of 4 -28, rating their satisfaction with services, support and treatment, involvement in decision making and whether they felt listened to and understood. Both treatment and control families scored highly on the FEI with a small but significant increase for FA with a mean of 24 compared to 22.4 for controls (p<0.001). Workers also rated families' co-operation, but this was not significantly different at follow-up.

Cameron and Freymond (66) conducted a quasi-experimental study of DR using accessible locally based child welfare offices compared to centralised offices using a traditional approach in Ontario, Canada. Data were collected from 261 parents at the start of services and 10 months later. Parents were more positive about DR services; 65% said they would refer a friend to DR services compared to 39% receiving traditional approaches at central offices (p<0.05). 61% of DR parents said they would seek help in future compared to 41% (p<0.05). At central offices 60% of parents said they would not seek help again compared to 39% of DR parents.

These studies show at best a small benefit of using more supportive approaches for families with child protection concerns rather than investigations to prove or discount allegations of abuse or neglect. However, UK based child protection assessments generally take a holistic route of supporting families, leaving investigation of perpetrators as predominantly a police matter, although integrated within a multi-agency process involving health providers and children's social care.

SafeCare

SafeCare (67) is a USA modular home-treatment programme designed for the treatment and prevention of child abuse and neglect in families with children aged less than 5 years. It covers home safety, child health and parent-child interaction, using behavioural methods to teach basic parenting skills. Damashek, et al. (68) conducted a RCT of SafeCare compared to services as usual (SAU) in families receiving child welfare services. SAU families were offered services specific to identified needs such as parenting skills, employment and social support. Both groups of families received intensive support with visits of 2 hours a week for up to 6 months, as well as discretionary hardship payments up to US$600. 1305 parents took part, 48% received SafeCare, 52% SAU. Families identified goals, and at the end of treatment providers rated goal completion on a 1 to 4 scale. There was a small statistically significant benefit for SafeCare but overall ratings of goal completion were high for both groups. The SafeCare mean goal completion score was 3.5, (SD 0.9) and SAU mean score 3.3, (SD 1.1; t(638)=2.6, p=.01). Bolt (69) evaluated SafeCare delivered to 93 families in Georgia and found that only 42% of families completed the programme, suggesting that outside of research projects parental engagement may be low. These two studies suggest that SafeCare may have a limited impact on parental engagement.

Motivational Interviewing

Motivational Interviewing (MI) aims to strengthen individual's motivation to change, build commitment, promote decisions for positive change and increase self-efficacy, it was originally used as part of treatments for alcohol addiction but is now used widely in many fields (70). Parents referred to child protection services may have low motivation to change their behaviours as they may not recognise or agree with the issues of concern to professionals. Most parent-training programmes were not designed for families in child welfare services, and parents may lack motivation if they are mandated to attend. Motivational Interviewing interventions aim to increase parents' motivation to change and has been studied in families involved with child protection systems.

Chaffin, et al. (71) compared the effect of MI in an RCT of two different parenting programmes in families who were referred following a child protection referral. Parents received either a pre-parenting programme MI group intervention, or a standard group information session, following these sessions parents were randomised again to either Parent- Child Interaction Therapy (PCIT) a dyadic behaviour parent training program, or a standard didactic group parent training program. Survival analysis was calculated based on attendance data from the 12 scheduled sessions for either PCIT or standard parent training. MI followed by PCIT had significantly higher retention in programme rates than all other combinations. Cumulative survival for the MI–PCIT combination was 85% (estimated survival time = 11.4, 95% CI = 10.8 to 12.0), compared to 56% for MI–standard (estimated survival time = 9.1, 95% CI = 7.8 to 10.4), 64% for standard–PCIT (estimated survival time = 9.2, 95% CI = 7.8 to 10.6), and 64% for standard–standard (estimated survival time = 9.1, 95% CI = 7.7 to 10.4).

Forrester, et al. (72) conducted a RCT of MI in child protection cases compared with standard management in one London local authority. Social workers were trained in MI, and families randomised after referral for child protection to be allocated a MI trained social worker (n=67) or standard social worker (n=98). There was no significant difference in parental engagement as measured using the Working Alliance Inventory (WAI) between the MI group and standard social work group.

Motivational Interviewing combined with SafeCare

Damashek, et al. (73) conducted a RCT of SafeCare with Motivational Interviewing and additional training for home visitors in identification of maltreatment, mental health problems, substance abuse and domestic violence (SC+) compared to services at usual (SAU) for families with children considered to be at high risk of child maltreatment. Eligible families had substance abuse, mental health problems or domestic violence but excluded those known to child welfare (protection) services. 398 mothers of children under 5 years of age took part, 204 were randomised to SC+ and 194 to SAU. Data were obtained from providers records on service enrolment and completion. There was a highly significant benefit from SC+ with 80% enrolled in SC+ compared to 49% enrolment in SAU treatment programmes (OR 4.3 2.6-7.0 P<0.001), of those who enrolled in SC+ 50% completed the programme compared to 21% receiving SAU (OR8.5 3.3-22.1, P<0.001).

A similar RCT by Silovsky et al. (74) based in rural South-West USA, compared SC+ with a control of community based mental health services of individual and family therapy tailored to families' needs. 48 families received SC+ and 57 SAU. SC+ clients were significantly more likely to engage with services, 83% SC+ completed initial assessment interview compared to 33% control (p<0.001), SC+ families attended more treatment sessions with a mean of 36 hours total compared to 8 hours for control (p<0.001). However, less than half of SC+ participants completed all 3 SafeCare modules.

In summary three RCTs (71, 73, 74) showed a benefit of MI combined with SafeCare or dyadic behavioural parent training programme, but one RCT (72) showed no benefit of MI in English child protection social work practice. Differences in the pattern of approach between UK and US child protection work may account for the lack of an effect of MI in the English study.

Comprehensive substance misuse treatment programmes

Comprehensive substance misuse treatment programmes work across systems to co-ordinate health treatment and social care support for affected families. These potentially could provide better management than fragmented approaches from different services.

Morgenstern, et al. (75) conducted a RCT of intensive case management (ICM) compared to usual care (UC) for substance misusing women, recruited through welfare offices in New Jersey. ICM involved clients working with case managers identifying barriers to treatment, offering support, practical assistance and home visits. Clients received vouchers as an incentive to attend treatment. Care managers continued contact with clients alongside of drug treatment programmes, working with treatment staff to support clients. UC involved clients being referred to drug treatment clinical services and welfare services alone. 161 women were randomised to ICM and 141 to UC, engagement was determined by attendance at treatment sessions. There was significantly better engagement with ICM compared to UC; 66% of ICM initiated treatment compared to 50% for UC (p=0.0045), and ICM engagement rates were almost double those of UC rates 60% vs 34% (p=0.0001). Retention rates were more than twice as high among ICM clients compared with UC clients, 42% vs 18% (p=0.0001). ICM clients attended significantly more treatment days throughout the 15month period, 301 vs 182 (p=0.0001). Rates for programme completion also were almost twice as high among ICM clients than among UC clients, 43% vs 23% (p=0.0001).

Andrews, et al. (76) evaluated a comprehensive programme for substance misusing mothers, involving addiction treatment services, parenting support, child welfare, child health and development services in Toronto, Canada. A retrospective chart review of service use of 160 mothers was conducted. Mothers who were referred to the programme antenatally stayed engaged in the service for a mean of 27 months compared to 11 months for mothers who self-referred and 16 months for referrals from other healthcare professionals ($p<0.006$); antenatally referred mothers also attended a greater number of services. This would suggest that there may be a critical time for engaging high-risk mothers in treatment and health promotion services.

Stover (77) conducted a very small RCT (n=17) of a comprehensive treatment programme for fathers with substance abuse and domestic violence, that included parenting support, compared with stand-alone drug treatment services. 66% of fathers receiving the comprehensive programme compared to 33% of controls completed at least 13/16 treatment sessions but this was not a significant difference.

Dakof, et al. (78) evaluated a comprehensive court based programme for drug abusing mothers, the Engaging Moms Programme (EMP), this involved case workers helping mothers comply with court orders by focusing on improving motivation, emotional wellbeing, and parenting skills. EMP is based on the theory and method of Multidimensional Family Therapy (79). Court outcome data were compared for cases receiving standard treatment prior to the start of EMP (n=37) and with EMP(n=43). Standard treatment involved intensive case management, with mothers having regular meetings with case managers who coordinated treatment services, monitored compliance and provided advocacy. 72% of mothers receiving EMP completed all drug court requirements compared to 38% receiving standard treatment ($p=0.002$), this was a significant benefit. However, Dakof, et al. (80) conducted a RCT of EMP (n=31) compared to standard intensive case management (n=31) in Florida Drug Courts which showed no significant benefit with no difference in treatment drop-out rates or rates of completion of court requirements between the groups.

In summary, four studies, including one RCT, found some benefit of comprehensive drug treatment programmes for increasing engagement but another RCT found no benefit.

Technology assisted interventions

There were two trials of technology assisted interventions, neither of which found any significant benefit. Bigelow, et al. (81) conducted a RCT (n=19) of mobile phone enhanced planned activities training (PAT) compared to standard PAT; a home visiting intervention aimed at improving parent-child interaction in families with maltreatment concerns. Intervention parents received text messages reinforcing PAT techniques and enabling easier rescheduling of appointments. 16% of enhanced PAT parents did not complete the programme compared to 30% of the standard PAT although this was not significantly different.

Baggett, et al. (82) conducted a RCT (n= 159) of different internet parent training programmes aimed at reducing the risk of child maltreatment. One programme focussed on play and learning to improve maternal sensitivity to protect against maltreatment, and the other on general developmental awareness. There was no significant difference in parental engagement between the programmes based on the number of internet sessions accessed.

Qualitative Engagement Papers

Barriers identified

All the studies noted barriers to parental engagement in programmes including: lack of motivation or recognition of need to change, limited time with children allowed for in programmes, not culturally applicable outside white families, feeling pre-judged and blamed – all of these were particularly noted in respect of the TripleP programme in a study which interviewed 34 families referred to child welfare - 75% of whose children had been placed in kinship or foster care (83). These barriers were illustrated in other studies including a review of parent advocates in the USA (84) which reported stigma, attitudes of child welfare workers, mistrust and prior negative experiences of child protection services as key barriers to engagement.

Six themes emerged in the review of qualitative studies to improve engagement:

- Relationship-based practice
- Skills development focus
- Home visiting
- Parent advocates
- Combined drug treatment programmes
- Supported housing

Relationship-based practice

In the one Canadian study, Gockell et al (85) report reflections of 35 parents whose child protection social workers referred them to family preservation programmes. Rather than considering intervention components, the data reports that parents identified that workers in effective programmes used specific relational skills to recreate a nurturing family environment that fostered parent engagement and change throughout the process of intervention. The programme comprised home visiting and group parenting skills, counselling peer support and education. Some were provided on site with childcare. Factors promoting engagement identified by parents were *interpersonal warmth and non-judgmental acceptance, programme and staff responsiveness and flexibility and a focus on client strengths*. The authors conclude the importance of qualitative research that focuses on client and worker perspectives by reaffirming the paramount impact of service relationships as a cornerstone of effective interventions from an evidence-based perspective.

Extending the focus on relationship-based, 'helping practices', were two studies that emphasised the worker-parent dyad relationship and how this supported parental engagement neighbourhood-based programmes in the USA (86, 87). In the Altman (87) study qualitative interview data were collected with 74 worker-parent dyads about neighbourhood based child welfare services and seven main themes, as revealed in the qualitative data were common across all participant groups: (a) the need for families and workers to set common and clear goals together; (b) the need for all involved to maintain a sense of hopefulness during the change process; (c) the need for parents to be aware of, acknowledge, and understand their situations accurately; (d) the need for all parties to be consistently motivated in their change efforts; (e) the need for workers to identify, understand and respect cultural differences in their relationships with families; (f) the need for truthful, honest, and respectful communication; and (g) the need for persistent, diligent, and timely work by all parties.

In the Witkin (86) study, data were collected from 170 families, who engaged in focus groups and completed surveys regarding their experiences in the Partnership for Families Programme (PFF), a community-based child maltreatment prevention program. The findings include*: parental improved self-confidence, improved communication in the home, openness to new friendships, improved patience and greater communication with children, less arguing, improved service engagement and engagements in wider community, reduced social isolation & improved parenting*. The focus on relationship-based practice *and* neighbourhood relevant programmes seem to be strong indicators of not only parental satisfaction but also engagement. Parents felt that they had more self-confidence and better ability to regulate their stress after participating in PFF services. In addition to increased attention to self-care, parents reported improvements in parenting skills and knowledge. Specifically, parents described using new skills with their children, such as fostering open communication and implementing behaviour reward systems. Further, they reported having better communication with their spouses/partners.

Skills development focus

Whilst the study by Garcia et al (83) primarily identified barriers to parental engagement using the TripleP programme, it is also important to note that given the programme's focus on developing parenting skills that participants reported improvements in such skills. They reported TripleP was useful in helping them to manage their children's behaviour and build positive parent-child relationships. When engaged in TripleP, caregivers said that they had increased communication, learned effective disciplinary strategies, applied developmentally appropriate expectations, and saw an increase in positive and prosocial child behaviours. However, this study was undertaken with parents mandated to attend by courts as they were involved with the child welfare system. It was noted however that engaging TripleP graduates to motivate and provide social support to new attendees (even those mandated to attend) was a useful engagement strategy, as was the importance of their progress in the programme being reported to their court caseworker and taken into account in court proceedings.

Home visiting

Both the Farrell et al (2012) study and Stalschmidt et al (2018) (88, 89) noted the increased receptiveness of child welfare families to home visiting and home-based delivery of services. In the Stalschmidt et al (2018) study whilst the families considered included 73 referred for child welfare services, data collected were with two focus groups of child welfare caseworkers (n = 13 total); and a second focus group with Parents as Teachers (PAT) workers and early childhood education staff (n=12). The focus groups aimed to review delivery and receptiveness by families of Early Childhood Connections (ECC)- a service integration process that attempted to coordinate an evidence-supported home visiting programme (PAT) with usual child welfare care for intact families in a USA urban city and county context where the majority of the child welfare caseload is very low income and about 70% African American. The authors recognised a number of structural issues that impacted delivery of the programme and the ability to maintain consistent staff involvement as well as client engagement.

Parent advocates

Using parent advocates to support families with child protection proceedings was reported to have some impact on parental engagement (Featherstone and Fraser, 2012)(90). The study was the only one of the engagement studies conducted in England and comprised of mixed data collection about 52 families to evaluate an advocacy scheme for parents whose children were subject to child protection proceedings including a pilot project where co-operation between parents and professionals was an issue. Of the 52 families involved, 18 gave feedback- 13/18 families found advocacy helpful, 11/18 made it easier to work with the Local Authority, 6/18 felt it influenced case outcome. The study included data from 19 social workers for 23 cases, 2/3 social workers felt advocacy improved family engagement by increasing family understanding of process and LA concerns and helping parents to contribute to meetings. Data also included 12 conference chairs for 29 cases where 79% felt advocates increased parental engagement, as they enabled parents to participate fully in conference. Three cases studies reported illustrated the intersectionality of gender and ethnicity for parents with entrenched CP cases where mothers were often held responsible for behaviour of partners. Whilst a small evaluation, its authors claim it offers evidence that advocacy for parents facilitated improved engagement with professionals and allowed some parents to hear what was needed to ensure their children's safety.

Another small-scale study in the USA also reviewed parents' perspectives on the role of parent advocates within the Child Welfare Organizing Project (CWOP) in New York City (84). CWOP trains parent advocates to support birth families at child safety conferences. The representative/ advocate gives parents support and information on the process and their rights. Barriers to engagement included stigma of child protection referral and negativity about referral, lack of trust in child protection workers, lack of knowledge of the parent representative role. However, the study reports that the shared experience of parent representatives helped families to engage with representatives and court processes, where representatives were viewed as separate from CPS workers. This was seen to be particularly beneficial for what they termed 'involuntary clients'.

As a form of parent advocate, peer mentors are parents who have successfully navigated the child welfare system who are paired up with parents currently experiencing the system and in many programmes there is a focus on parent advocates helping parents to become less socially isolated and develop their social networks**.** The study by Berrick et al (2011) (91) collected data with 25 parent clients and six peer mentors and revealed three distinct themes of: *Value of shared experiences (including encouragement, trust and hope), communication (clarity, availability, frequency and ability to communicate on their behalf with other professionals) and support (emotional, material, support in developing self-reliance and support with substance misuse)*. There were also reported to be positive impacts on the peer mentors themselves, although this raised questions about the sustainability of the model as peer mentors sought to pursue education and other personal development opportunities and moved away from their mentoring role.

Combined drug treatment programmes

Two studies explored parents' experiences of engagement with programmes that focused both on child welfare and substance abuse amongst parents (92, 93). The study by Akin et al (2018) explored parental experiences of the Strengthening Families program, a group parenting programme for drug misusing parents and collected telephone interview data with 10 parents. Whilst the study was conducted in the USA, Strengthening Families is a popular programme in the UK and as such the insights could have relevance to this context. The themes that emerged emphasised that whilst individual factors were important indicators of engagement, particularly motivation (being mandated was a negative motivator); programme and provider factors were much more important to ongoing engagement. Programmatic features that were seen to be enablers were *timing, format and transportation* and included the importance of beginning sessions with a group meal which helped them to teach their children skills together, overcoming transport barriers and the ability to have separate parent and child groups as well as groups together. Provider factors included the ability of facilitators to manage group dynamics, the importance of the relationship and rapport that was possible with facilitators that they perceived to be highly skilled, caring and well prepared.

Both the Akin et al (2018) and Seay et al (2017) reported drug treatment programmes that were mandated by courts. In the Seay et al (2017) study there was a clear focus on engagement with the programme as a requirement of parents (primarily mothers) keeping their children, as they were all engaged with CPS, so there was an element of coerced engagement. However in their focus groups with 45 parents it became evident that this was not completely causal, and whilst for some having a child (and wanting to keep their child) was a motivator to engage in drug treatment, in order to be a better parent; for others their child(ren) became inhibitors to their engagement in the programme. Specific reasons included not wanting to be away from their child, the demands of being a parent and managing their overwhelming guilt. As such the paper identified a number of strategies that encouraged and supported engagement including *mother-child residential programmes*; *specific parent-child therapies* including child and family therapy, children's activities and childcare; *material support* for other needs such as housing, contraception, support with accessing hospital appointments; *treatment workers acting as advocates* for families and the provision of emotional support from workers.

Supported housing

One study combined data collection with parents where there was both a child protection concern and unstable living arrangements (Farrell et al, 2012) (89). Whilst it was relatively small-scale and comprised only 41 parents, a resultant mean score of 5.67/6 on their engagement scale suggested clients highly engaged with the programme. This consisted of a supportive housing programme for families referred to child welfare services to address housing needs, mental health and parenting, and safeguarding. The authors claimed that a clear focus on housing with tangible goals may have helped engagement. Clients may have worked better with housing officers as they were separate to the child welfare officers (although informed and worked with them). Parents felt more engaged with the housing team than child welfare professionals, but the combination of regular contact with a case worker and home visiting seemed to improve overall engagement.

4.4.3. Decision making for the infant sleep environment in families with children considered to be at high risk for SUDI.

What does qualitative research tell us about the factors that influence decision making for the infant sleep environment, in families with children considered to be at high risk of SUDI, and how can we use this insight to improve intervention design and delivery?

Six themes were developed from the 15 papers included in the review:

1. Knowledge as different from action
2. External advice must be credible
3. Comfort, convenience and disruption to the routine
4. Plausibility, mechanisms of protection
5. Meanings of safety, risk mitigation using alternative strategies
6. Parents' own expertise, experience and instincts

Qualitative research predominantly uses theory in order to provide insights from collective accounts, these are the 'themes' which are reported, and which we have synthesised here. In this synthesis of themes, we were aware that papers varied in their descriptions and interpretations. Noyes and Popay (18) use 'thickness of the description of the subjective experience and meanings they provided' as an additional quality appraisal. In this way, the contribution of each paper to the overall synthesis can be portrayed. We have used this framework to demonstrate where each paper has contributed to the synthesised themes presented here and this is shown in Table 7:

Table 7: Themes and thickness of description from included decision-making papers

	Theme and thickness of description					
Source Paper, n=15	Knowledge as different from action	External advice must be credible	Comfort, convenience and disruption to the routine	Plausibility, mechanisms of protection	Meanings of safety, risk mitigation using alternative strategies	Parents' own expertise, experience and instincts
Tipene-Leach *et al.* (2000)	Thick	Thin	Thin			Thin
Mosley *et al.* (2007)	Thick	Thick	Thin		Thick	Thick
Miller *et al.* (2008)	Thick	Thick	Thin	Thin	Thick	Thin
Chainese *et al.* (2009)			Thick		Thick	Thin
Joyner *et al.* (2010)			Thick		Thick	
Moon *et al.* (2010)		Thin	Thin	Thick	Thick	Thick
Ajao *et al.* (2011)			Thick		Thick	
Yuma-Guerrero *et al.* (2013)	Thick	Thin	Thin			
Gaydos *et al.* (2015)	Thick	Thin	Thick		Thin	Thin
Herman *et al.* (2015)	Thin		Thick	Thin	Thick	
Caraballo *et al.* (2016)	Thin	Thin	Thin	Thin		Thick
Crane & Ball (2016)	Thick	Thick	Thin	Thick	Thick	
Joyner *et al.* (2016)			Thick	Thin		
Clarke (2016)	Thick	Thick	Thick	Thin	Thick	Thick
Pease *et al.* (2017)		Thick	Thin	Thick	Thick	Thick
Ellis (2019)	Thick	Thick	Thick	Thick	Thin	Thick

Knowledge as different from action

In the papers which described knowledge of safer sleep, almost all participants had heard advice about reducing the risks in the infant sleep environment. Gaydos et al. (48) reported high awareness and understanding of the safer sleep recommendations in the US, which included advice not to bedshare at the time. They also reported all but three of the 60 participants had shared a bed with their baby. Similarly, Miller et al. found examples where knowledge of recommended practice was not enough on its own to influence practice. Participants would cite the advice, then follow it with a reason why it didn't happen with their baby. Clarke set out to investigate how knowledge influences behaviour and concluded that "It is too simplistic to assume that knowledge of risks leads to behaviour change" (53). The detailed reasons for this lack of impact from knowledge alone is described in the other 5 themes in this analysis, but it emerged as a theme in its own right given that the majority of interventions that have proven to be successful in reducing sudden and unexpected deaths in infancy have had information giving at their heart. The field of SIDS in particular has seen the success of back sleeping campaigns, leaflets, advice and a fairly didactic approach in the past, so it was interesting that this clear chasm between having knowledge and acting upon it should be so marked. Mosley et al. described a 'chorus' of the back to sleep message, but how this was then not translated into action. Crane & Ball (57) described comprehensive knowledge, but variability in implementation. Many of the studies then attempted to map the thinking and behaviour that took up the space between having knowledge and actual practice. Overall, the consensus is clear that knowledge is not enough in this arena and that interventions must go far beyond information giving to be effective for this group.

External advice must be credible

Across most studies, there were descriptions of participant reactions to the safer sleep advice. Yuma-Guerrero et al. for example, found that some participants felt that the advice given to them was ‘ridiculous’. There were other examples where participants found the advice, especially changes to the advice or inconsistencies across professional groups was confusing, and left parents feeling unsure about the specific details of exactly what a safer sleep environment looks like. Miller et al. (55) reported confusion as a major theme, with parents citing conflicting advice from health professionals. In Mosely et al’s study (43), they found evidence of ‘tension’ between external advisors to parents, in particular between health professionals and older family members. Pease et al (54) found credibility of advice to be lacking where didactic approaches were used by health professionals, and Ellis (56) similarly termed this ‘bad advice’ where mothers described several factors that contributed to ignoring advice, including inconsistencies and perceptions of ‘dinosaur’ advice that was outdated or did not apply to them. Inconsistencies may be perceived – infant safer sleep needs do change over the first few months, so it will be important to include these changes as normal, rather than leave parents feeling as if the advice has changed without reason. Trust in advice seems vital for messages to become embedded into practice, but it competes against conflicting information which sometimes seems more pertinent, especially if it allows night-time care of the infant to be easier for parents. Clarke’s study found that health professionals were seen as only one of a range of potential sources which included partners, peers and family members (53). No studies analysed the impact of safer sleep advice on fathers, separately. However, fathers or partners were included in half of the studies in the synthesis. How to make advice more credible will be a key factor in any future intervention for this group, and fathers and partners will undoubtedly play an important role in how this advice will be viewed and implemented. Approaches should avoid being didactic, should be consistent and come from trusted sources, including peers, partners and wider family members.

Comfort, convenience, and disruption to the routine

One of the most salient themes across all studies describing why parents don’t follow the recommended safer sleep advice involved descriptions of comfort, convenience or disruptions to routines. Every study described this theme in one way or another, even where it wasn’t reported as a major theme. Infant sleep position was commonly reported in relation to infant comfort where parents perceived infants as more comfortable in unsafe sleep positions (42, 50, 52). This idea of comfort as also related to how parents perceived their infants as in charge of sleep decisions, citing infant preference for certain positions or environments (56). Decisions to bedshare, especially if breastfeeding, were often cited as related to convenience, as a way to minimise time spent awake during the night (42, 49, 52, 56). Similarly, changes to the infant sleep environment that resulted from disruptions to the routine almost always related to enabling both parent and child to get enough sleep (46, 48, 49, 53, 54). Disruptions to the routine involved a range of factors including changes to the sleep environment due to tiredness or sleep deprivation, changes at weekends, and disruptions to the wider family environment. Clarke describes how ‘makeshift’ sleep environments were designed to be conducive to sleep rather than safety (53). Pease et al. (54) outlined two types of disruption; those that were unintentional such as falling asleep with the baby on the sofa, or intentional but rare, with mothers expressing a certain amount of tolerance for unsafe sleeping situations as long as they were not the norm. Ellis too, describes occasional situations where preservation of sleep is prioritised over maintaining the safe infant sleep environment (56). Coping with sleep deprivation and night waking were challenges to maintaining infant safety in this group. Interventions should employ a theoretical underpinning which includes the complex and often tiring nature of caring for a young baby.

Plausibility, mechanisms of protection

This theme first appears in our literature in 2008 in the UK study by Miller et al (55). They noticed that some parents were engaging in safe infant sleep practices but were not aware that these practices reduced the risk for their infant, and postulated that if parents knew why the advice reduces the risk they may be more likely to follow it. Plausibility is then noted as a major theme in the study by Moon et al, where the authors found that where mothers were unable to connect a mechanism of protection to a piece of safer sleep advice, it left room for doubt and ultimately reasons not to follow it. They also noted that, where advice was seen as plausible, this was connected to understandings of how an infant might suffocate, especially in advice about sleeping position and bedding. Understanding how the advice protects infants, or having a reason for the advice was echoed similarly in the studies by Herman et al., Caraballo et al., and Crane & Ball (47, 50, 57). Joyner et al. looked specifically at dummy/pacifier use and again found that parents were curious about the possible mechanism of protection from using a dummy/pacifier (45). Pease et al. also describe the need for a connection between the specific advice and safety and mentions advice which is more readily accepted such as the ‘feet to foot’ message. The inherent plausibility of placing a baby of the bottom of the cot to prevent head covering by wriggling under blankets is enough for parents to feel confident in following this advice. Both Pease et al and Ellis found that a lack of understanding of the reasons for the advice were tied into feelings of being ‘told’ or just given rules and expected to follow them without question (54, 56). Future interventions should consider how mechanisms of protection are explained alongside the traditional safer sleep messages. Given that these mechanisms are all also related to sleep related accidental suffocation, it may be of use to parents to understand how safer sleep advice specifically protects a baby’s airways.

Meanings of safety, risk mitigation using alternative strategies

The majority of studies included in this review found parents were concerned about safety of their infants and had developed different ways to interpret threats to safety within their infant’s sleep environment. Chainese et al., and Joyner et al. both describe safety as a reason for sharing a bed with an infant, predominantly to improve monitoring of the infant and to protect against external threats including gunfire, house fire, vermin or violent older sibling (46, 49). Bed-sharing for closeness, which improved perceived infant monitoring during illness was also common (43, 47, 50). Studies also reported variation in how risk information was interpreted, terms like ‘firm’ had different meanings in the study by Ajao et al. (51). These meanings of safety extended beyond how safer sleep messages were implemented, into a range of infant sleep practices that were designed to improve safety for infants, but in many cases, inadvertently increased the risks to infants. Examples of this include the use of cot bumpers to prevent injury to infants from cot bars (50), pillows in bed-sharing scenarios to prevent rolling or falling (48), and movement monitors in place of back sleeping (53, 54). Using alternative strategies to maintain safety without necessarily adhering to safer sleep advice was also related to understanding of SIDS as a ‘unknown cause of death’. Studies reported that parents found it hard to accept risk reduction advice for something they saw as random, fated, or within a context of destiny (44, 46, 47). This made filling in their own safety strategies more palatable, or even using luck as risk reduction as seen in the study by Ellis (56). Fatalism was used to describe things that were difficult to change in the Clarke study, for example smoking. Mothers also used increased checking of the infant while asleep to reduce anxiety about sleep environment risks (44, 53, 54). Understanding that safer sleep advice is translated and implemented in a variety of ways, which doesn't always meet the infant's need for safety could be used to develop interventions that avoid giving advice that is prone to misinterpretation. Interventions that use the principles of an infant's need for safety during sleep, that focus on how and why babies should sleep on their backs with their faces clear, and in a safe space, may limit misinterpretations and use of alternative, unsafe, strategies.

Parents' own expertise, experience and instincts

The final theme from this synthesis explores meanings of parenthood and factors which influence how safer sleep advice is implemented within these meanings. Tipene-Leach et al. describe how parents need to be autonomous in their parenting, and how advice that conflicted with their own instincts provided a source of tension (52). Similarly, Clarke describes the conflict between intuition and "doing it by the book" (53). Ellis explored both validation and expertise as important to young parents in her study (56). In their development of expertise, previous experience was heavily related to reasons given for not following safer sleep advice. This was especially seen if not following the advice previously went without incident. This made it seem less risky to ignore for subsequent children (47). Yuma-Guerrero et al. sum this up in their paper with the quote: "I did this with you when you were little, and you were fine" (42). Related to both experience and expertise were themes that described how parents would use their instincts while making decisions for the infant sleep environment. This was particularly seen in papers where parents described co-sleeping scenarios as safe because of their ability to know where their infant was despite also being asleep (43, 47, 49, 54). A participant in the Pease et al. study calls this the 'mum sleep' (54). Valuing the need for parents to feel confident in their expertise means allowing a certain amount of autonomy and ability to make decisions for themselves and their infants. Future advice and guidance to families with children considered to be at risk should take parents' own experience into account and tailor the content of safer sleep conversations to each families' needs.

5. Discussion

5.1. Summary of Evidence

5.1.1. Interventions

There is good evidence that multi-modal interventions that provide a safe infant sleep space along 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. Several interventions engage peer educators or a mechanism of ‘paying-it-forward’, using intervention participants to spread infant safety messages further into communities and to reach traditionally viewed ‘hard to reach’ and vulnerable populations. Such interventions offer a scalable and achievable method to share safer sleep messages which need not be resource heavy. 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. Long-term provision (for example up to the sixth postnatal month) builds on the initial contact and can provide both support for parents and opportunities for professionals to identify changes in both the sleep environment and infant care practices which might decrease the risk of SUDI and SIDS. Culturally appropriate agencies, such as the Maori agencies in New Zealand, seemed to have better engagement from these previously hard to reach families. This could provide a model for practice in England with culturally diverse populations. Interventions that have been subsumed into ‘usual service provision’ have delivered sustainable improvements in reducing risks for SUDI and SIDS for infants, and resultant decreases in infant mortality rates. While providing three papers, only one digital intervention was available for review and was not effective in reporting knowledge improvement and behaviour change, except for reducing the use of soft bedding. While the majority of the data reported on in these intervention papers were parental self-report, several studies identify decreases in infant mortality and SIDS rates, which, while not shown to be a clear consequence of the interventions, raise the possibility that increased knowledge and adherence to safer sleep recommendations is a valid outcome of these interventions.

5.1.2. Engagement

There is 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, and close working and co-ordination between agencies such as programmes that combined substance misuse treatment with parenting support. Barriers to engagement include 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. A flexible approach to tailoring the number, duration and content of health professional visits/ contacts was also welcomed by families and supported improved engagement.

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. Our review highlights the importance of relationship-based practice and the characteristics of these relationship reported to be important: trust, non-stigmatising, and non-judgemental. An approach that focuses on the wider needs of the family including housing and mental health needs is also important.

Two technology assisted interventions were not found to be effective, however it is worth noting that these types of 'digital health' options are becoming more popular, particularly within the UK response to the SARS-COV-2 global pandemic. There may be a long-term impact from the pandemic on how personal services are provided to families with young children in future – services may be less likely to be face to face, more linked to the use of technology such as mobile phones or phone Apps, and to be more targeted to families with particular needs or risks. Studies showing the relative ineffectiveness of technology-based interventions may need to be repeated using better population selection and better technology. The rapid changes in communications seen during the pandemic may mean that some of the features of digital health interventions that made them less effective in the past may be less of an impediment in the future.

In summary, our review found that effective engagement is facilitated by experienced professionals given time to develop supportive non-judgemental relationships with families in their homes, working long-term, linking with communities and other services. Fragmentation of services, cuts to social care and reduction in Health Visiting will make engaging vulnerable families more difficult.

5.1.3. Decision-making for the infant sleep environment

The six themes identified across the literature provide robust insights into how parents with children considered to be at high risk for SUDI make decisions for the infant sleep environment. The themes paint a picture where knowledge alone is insufficient, conversations work best with trust and credibility, parents want to know the mechanisms of protection incorporated with advice that recognises their expertise, world views and priorities for sleep and wellbeing as well as safety. This review has uncovered important factors to consider when designing and testing interventions to improve uptake of safer sleep advice in families with children considered to be at high risk for SUDI. Understanding the context and motivations of parents with children at high risk when making decisions about infant sleep is an important step in designing interventions to change behaviour. The findings from this review may form the basis for innovations that attempt to address some of the factors that influence this decision making. Approaches to intervention design are many and varied, but those with a strong theoretical underpinning and transparent mechanism of action work best (94). One such approach, the COM-B model has been developed from a synthesis of existing intervention development frameworks (95). The model requires analysis of the capabilities, opportunities and motivations of the behaviours in question, identifies sources of behaviour and functions of interventions that can then be mapped to a behaviour change taxonomy (96). The taxonomy provides a detailed selection of behaviour change techniques which can be brought together in an intervention. This systematic approach to designing interventions improves transparency and enables future research to investigate in detail exactly how interventions work, and the circumstances within which they work best.

5.2. Strengths and Limitations

Our search of the grey literature and snowballing approach of relevant citations within the references of the records selected produced a further 42 papers in addition to the 3506 records identified which suggest our search terms were fairly comprehensive, our agreement rate on selection was high and enough papers were identified in each of the three topic areas for meaningful discussion.

There are however several limitations to this work. The quality of the papers reviewed is variable and synthesis is difficult given the limited and disparate ways in which studies have been reported.

The lack of controlled observations in some studies or comparing intentions of infant care practice before or around delivery as a baseline when the actual practice of caring for infants is often very different leads to a weak design and questionable conclusions. Most studies have understandably had to rely on maternal self-report rather than more objective measures which suggests potential subjective (‘social desirability’) bias in the findings cannot be ruled out.

In order to include the most relevant literature, the review used two separate but related populations of interest. Our findings relating to interventions to improve the uptake of safer sleep advice, and our findings that relate to decision making for the infant sleep environment are most relevant to families with children who are considered to be at high risk of SUDI. Our findings relating to interventions to improve engagement with support services are relevant to families with children who are considered to be at high risk of significant harm through abuse or neglect as there were no SUDI/SIDS focused studies revealed in this search.

In order to review interventions and decision making specific to families with children considered to be at high risk for SUDI, we relied on individual studies’ definitions of ‘high risk’. This meant that our included studies relate to a variety of populations, including high-risk cultural groups. Given infant care practices and the sleep environment are culture-specific, this was appropriate. While this means that our conclusions are drawn from a wider pool of literature, it does mean that care must be taken to consider the specific circumstances of our UK families with children considered to be at high risk of significant harm through abuse or neglect, in light of our findings. There will be some crossover in risk factors between these two populations, however some caution should be exercised when acting on these findings for those families in the UK with children considered to be at high risk of significant harm through abuse or neglect, this may be particularly true of interventions targeted to individual ethnic groups.

This also means that we did not include safer sleep interventions for the general population (e.g. Scotland’s nationwide cardboard baby box programme) as we would not be able to review their impact in families with children at risk separately.

A large majority of the engagement papers (23/28) were from North America, which may limit the applicability of some findings, given different child protection practices, different health care practices and an ethnically different population mix. Many of the engagement outcomes were based on attendance at treatment sessions only, not whether parents actually engaged with the messages given, therefore reducing the real effect of the intervention. The engagement studies were of variable quality with only 4 RCTs with n>200, and only 2 of these RCTs with a clinically significant increase in engagement.

5.3. Conclusions and implications

This review forms part of a wider project to review practices and make recommendations about how best to increase uptake of safer sleep advice in families with children considered to be at high risk of significant harm through abuse or neglect. We found no safer sleep intervention studies that specifically included this population, although several used overlapping risk factors. From the literature review we found evidence of how future interventions to improve safer sleep uptake should be designed and implemented for maximum impact in families with children considered to be at high risk for SUDI. While we have no evidence that approaches for families with children considered to be at high risk of significant harm through abuse or neglect should be any different to those with children at risk of SUDI, this review highlights how consideration of the specific challenges to each family should form an integral part of family support with advice about safer sleep. The implications of this review are outlined for practitioners/interventionists, policy makers and future research, below.

For practitioners/interventionists

- A non-judgemental, culturally sensitive, personal approach is required for families with children at risk providing evidence-based advice so they can make decisions on how to keep their infants safe.
- Health professionals should be provided with consistent advice that can be delivered in plain English to families with plausible explanations as to why this advice will keep their infant safe.
- Interventions need to use a strong theoretical underpinning, where the underlying assumptions about the links between the intervention and behaviour are clearly stated. To support this, interventions should have clear explanations, considering the needs for parents/carers to be provided with credible advice that incorporates mechanisms of protection which are understandable and account for the changing needs of a sleeping infant.
- Ideally conversations should begin in the antenatal period when families are most reliant on the health provision being offered.
- Future advice and guidance to families with children at risk should take parents' own experience into account and tailor the content of safer sleep conversations to each families' needs. Planning tools that acknowledge complexity and encourage parents and carers to design strategies for risk minimisation during disrupted routines should be explored in future research studies.
- Most studies in our review focussed on mothers, but the qualitative synthesis in particular, identified the importance of others. Future interventions should consider how they include partners, peers and wider family members to extend knowledge and understanding of safer sleep to all those who may be caring for a young baby.
- Interventions should, ideally, be delivered face to face. Innovations that consider how to capitalise on peer to peer models where information can be shared within community networks may be of use in this context.

For policy makers

- Interventions for this group should be embedded within existing service provision, with clear explanations of how they are supposed to work for those delivering them.
- Continuity of care from the antenatal to the postnatal period is important. Health visiting and community midwifery provide ideal opportunities to have meaningful conversations with

families continuing from the antenatal period through to the postnatal period. These conversations should follow the same underlying assumptions about how the intervention is supposed to work, so as to provide parents/carers with consistent and relevant information.
- There is some evidence that a service-wide approach targeting vulnerable families over a period of time can have direct impact on reducing infant mortality. Adequate time for health professionals to deliver safer sleep conversations should be provided and there was evidence that cuts to service provision make engaging families with support more difficult.

For future research

- New interventions should be developed and designed with the full and direct participation of parents/carers, partners, peers and wider family members, engaging the 'nothing about us without us' principle (4).
- Future intervention 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.
- Future research into the behaviour change techniques most applicable to safer sleep interventions in families with children considered to be at high risk may benefit from consideration of specific behavioural approaches such as the COM-B model of behaviour change (5).
- We found no evidence that supported the use of digital messaging or technology assisted interventions, although this was not the primary focus of our searches. With these types of intervention becoming more popular, and with the current SARS-COV-2 pandemic driving the need to find alternative support delivery options, future research should consider approaches to improve the effectiveness of digital health interventions for families with children considered to be at risk, and consult the literature on digital health intervention development.
- Approaches need to be flexible enough to allow health professionals to maximise on the trust and credibility they have developed with each family. Health professionals should be involved in the design and testing of future interventions in order to ensure their expertise is included.

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