

# Child Death Review Board

Queensland **Family & Child** Commission

**Issues paper: Sudden unexpected death  
in infancy among vulnerable families  
in Queensland**

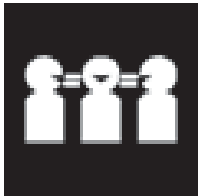
*A report prepared by the  
Queensland Paediatric Quality Council  
On behalf of the Child Death Review Board*

## About this report

The Child Death Review Board (CDRB) is an independent board established on 1 July 2020 to carry out reviews of the child protection system following the deaths of children connected to it. These reviews aim to identify opportunities for improvement in systems, legislation, policies, and practices and to identify mechanisms to help prevent deaths that may be avoidable.

This report has been prepared under section 29D of the *Family and Child Commission Act 2014* which enables the CDRB to carry out, or engage persons to carry out, research relevant to reviews of the child protection system following the deaths of children connected to it.

## Accessibility



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## Acknowledgements

The Queensland Child Death Review Board (CDRB) acknowledges Aboriginal and Torres Strait Islander peoples as the Traditional Custodians across the lands, seas and skies on which we walk, live and work.

We recognise Aboriginal and Torres Strait Islander peoples as two unique peoples, with their own rich and distinct cultures, strengths and knowledge. We celebrate the diversity of Aboriginal and Torres Strait Islander cultures across Queensland and pay our respects to their Elders past, present and emerging.

The CDRB recognises the rich and resilient cultures that continue to sustain and strengthen Aboriginal and Torres Strait Islander peoples. We respect the right to self-determination and the critical importance of continuing connection to kin, Country and culture in the lives of Aboriginal and Torres Strait Islander peoples.

The CDRB acknowledges the important work of the child protection system in protecting children and helping their families and communities to care for them. The CDRB remains committed to working with agencies and stakeholders to make the changes needed to promote the safety and wellbeing of children and help prevent future deaths.

The CDRB would like to thank Dr Rebecca Shipstone, Dr Julie McEniery and Dr Diane Cruice, researchers from Queensland Paediatric Quality Council (QPQC) who conducted this research. The QPQC is responsible for the analysis of clinical information about paediatric mortality and morbidity in Queensland and making recommendations to improve the safety and quality of health services statewide. The QPQC Infant Mortality Subcommittee has a focus on reducing the rate of infant death in Queensland, including SUDI.

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### Warning

*This report contains information about the deaths of children in Queensland. This report may cause distress for some people. If you need help or support, please contact any of these services:*

**Lifeline:** 13 11 14

**Beyond Blue:** 1300 22 4636

**Kids Helpline:** 1800 55 1800

*(for 5–25-year-olds)*

*Aboriginal and Torres Strait Islander peoples should be aware that this report contains information about deceased children and systemic issues facing Aboriginal and Torres Strait Islander peoples.*

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## Table of contents

<b>Acknowledgements</b> .....	<b>3</b>
<b>Executive Summary</b> .....	<b>5</b>
<b>Introduction</b> .....	<b>8</b>
Sudden Unexpected Deaths in Infancy (SUDI).....	8
Why do SUDI occur? .....	10
Changes in SUDI over time .....	12
<b>SUDI in the child protection population</b> .....	<b>14</b>
Factors contributing to SUDI in the child protection cohort .....	14
<b>SUDI risk reduction in the child protection population</b> .....	<b>18</b>
Decision making and barriers to adherence to SUDI risk reduction strategies .....	18
Best practice interventions for SUDI risk reduction in the child protection population .....	20
<b>Reducing SUDI in families known to the child protection system in Queensland</b> .....	<b>23</b>
Opportunities for system improvements .....	24
<b>References</b> .....	<b>28</b>
<b>Appendix 1</b> .....	<b>34</b>
Criteria for SIDS sub-categorisation according to the San Diego definition.....	34
<b>Appendix 2</b> .....	<b>35</b>
Determining the cause of death in SUDI cases.....	35

# Executive Summary

Sudden Unexpected Deaths in Infancy (SUDI)—defined as the sudden and unexpected death of an otherwise healthy infant, in which there is no immediately obvious cause of death—occur predominantly in Queensland’s most vulnerable populations. These include families known to the child protection system, Aboriginal and Torres Strait Islander families and other families experiencing social disadvantage and multiple adversities.

Infants known to the child protection system are significantly over-represented in the SUDI population. Half of the infant deaths reviewed by the Queensland Child Death Review Board (CDRB) in its first year of operation died suddenly and unexpectedly.\* In recognition of this, the CDRB Secretariat commissioned a review of the existing literature regarding SUDI within the child protection population with a view to informing system improvements in Queensland. Dr Rebecca Shipstone, Dr Julie McEniery and Dr Diane Cruice, researchers from Queensland Paediatric Quality Council (QPQC) were identified as best placed to conduct this research.

This Issues Paper provides an overview of SUDI among families known to the child protection system. It reviews existing literature to identify the components of a successful intervention model for vulnerable families.

## KEY FINDINGS

The majority of SUDI in families known to the child protection system occur in highly hazardous sleep environments, frequently while sharing a sleep surface in the context of parental smoking and alcohol and other substance use. A range of other sociodemographic risk factors are also significantly more common in this vulnerable cohort, including unemployment, substance misuse, domestic violence, mental ill-health, criminal offending and intergenerational trauma.

Research has demonstrated that socially vulnerable families have fallen behind in their uptake of safer infant care and safer sleep recommendations. Families known to the child protection system experience barriers to implementing SUDI risk reduction strategies.

There is currently no published research regarding effective SUDI risk reduction strategies in the child protection population. However, literature is available on decision making and risk reduction interventions in families at high risk of SUDI and strategies to improve service engagement with them. This literature has been used to identify the components needed to reduce SUDI in families known to the child protection system.

Any service or intervention likely to be effective must be underpinned by a family centred, relationship-based continuity model of care. A harm reduction approach which empowers parents to make small incremental changes is also critical to reduce risk.

Optimal programs for families at high risk of SUDI in the child protection population should also include:

- Support for families to address the broader social and economic disparities experienced.
- Longer term, face-to-face services with high-intensity family contact and collaborative working relationships between statutory agencies and non-government support services. These should seek to address both social and economic concerns and provide parenting support.
- The establishment of strong, reciprocal links with other relevant services.

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\* Since its commencement in July 2020, the CDRB has been notified of 104 deaths of children known to the Queensland child protection system, of which 20 were classified as SUDI. In its first year of operation, the CDRB reviewed 55 child deaths, 18 of whom were infants. Nine of these 18 infant deaths were classified as SUDI.

In addition, SUDI-specific programs for families at highest risk should:

- Respond and be tailored to each family's unique circumstances, concerns and needs.
- Support parents to plan for safety at every sleep, even when routines may be disrupted.
- Establish clear links between risk reduction strategies and mechanisms of risk and protection.
- Actively address and dispel common myths.
- Take a whole-of-family/social network approach.
- Provide multimodal interventions to establish a safe infant sleep space coupled with a comprehensive face-to-face education program.

## FOCUS AREAS FOR SYSTEM IMPROVEMENT

This review has highlighted the absence of research to establish best-practice SUDI risk reduction interventions specifically within the child protection population. Opportunity exists for the CDRB to promote the need for further research in this area and to facilitate this through the provision of relevant data, either alone or in collaboration with agencies such as the QFCC and the QPQC.

Despite the lack of research about effective intervention with families known to the child protection system, findings from the literature regarding families at risk of SUDI have been instructive in identifying the core components of required system improvements. In preparing this paper, the QPQC has identified three focus areas for system improvement the CDRB may wish to consider.

### Focus Area One

*Clear and timely multi-agency, bi-directional referral pathways for families with infants and young children experiencing multiple risk factors known to place infants at risk of SUDI and coexisting child protection concerns should be developed.*

- A collaboration between the Department of Children, Youth Justice and Multicultural Affairs (Child Safety), relevant entities within Queensland Health, Primary Health Networks, non-government service providers and consumer representatives should be developed.
- This collaboration should seek to review existing local practice and articulate a model of service provision that provides an effective, collaborative, family-centred approach that can be tailored to reflect local knowledge, cultural backgrounds and local services.
- In doing so, this collaboration should consider current challenges within the Queensland context, including decentralised service models, co-ordination of messaging across service providers, and the ability of services to engage vulnerable families.

### Focus Area Two

*The integration of infant sleep safety assessments and the provision of safer sleep advice into existing assessment and planning with families to reduce child protection concerns should be considered the responsibility of all services involved with these families.*

- SUDI risk reduction must be promoted as the responsibility of all services working with families, particularly vulnerable families experiencing child protection concerns.
- A co-ordinated approach would provide the opportunity for all services working with such families to provide consistent, best-practice messaging about safer infant sleeping and infant safety in general and support in-home sleep safety assessments to be conducted.

- Such interventions should occur across the first year of life, adapting to suit major developmental milestones.

### Focus Area Three

*Opportunities for the statewide implementation of multimodal programs (such as the Pēpi-Pod® Program) known to assist families to implement safer infant sleep practices should be explored as an integral component of a multi-agency, targeted safer sleep initiative.*

- Any co-ordinated, multi-agency intervention to address infant safety and safe infant sleeping in at-risk families, including those known to the child protection system, should consider existing Queensland initiatives.
- The Pēpi-Pod® Program, in particular, has shown encouraging results on evaluation and been recommended for expansion.
- Initiatives are underway within Queensland Health to pilot broader implementation within standard postnatal care.

# Introduction

The following Issues Paper has been prepared by the Queensland Paediatric Quality Council (QPQC) (Dr. Rebecca Shipstone, Dr. Diane Cruice and Dr. Julie McEniery) on behalf of the Queensland Family and Child Commission acting as an agent of the Queensland Child Death Review Board.

This paper provides important information about SUDI among families known to the child protection system, and other vulnerable families in Queensland. Specifically, this paper:

- Provides a clear definition of SUDI and a high-level overview of the associated risk factors.
- Identifies children known to the child protection system as an at-risk cohort for SUDI, and presents data relating to the prevalence of SUDI among these socially vulnerable families, compared with the general population.
- Outlines some of the challenges in reaching at-risk families with traditional interventions designed to reduce the risk of SUDI.
- Describes best-practice interventions specifically targeted towards vulnerable or at-risk families and highlights research gaps that may exist.
- Identifies the essential components of a successful intervention model for vulnerable families to reduce the rate of SUDI among infants known to the child protection system in Queensland.
- Highlights potential opportunities for system improvements in Queensland and provides recommendations for next steps that would be required.

## Sudden Unexpected Deaths in Infancy (SUDI)

Sudden Unexpected Deaths in Infancy (SUDI) is a mortality grouping, used primarily for research purposes, that describes the sudden and unexpected death of an otherwise healthy infant (aged less than one year), in which there is no immediately apparent cause of death.<sup>1-6</sup> SUDI is not a cause of death—infant deaths classified as SUDI may occur from a variety of causes. However, studying sudden and unexpected infant deaths together helps to identify factors common to a range of infant deaths occurring in similar circumstances and, most importantly, those factors that may be preventable or amenable to change.

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*There is no internationally agreed definition of SUDI. However, most researchers in Australia, and many internationally, concur that deaths that meet all the following criteria should be classified as SUDI:*

- *an infant aged less than one year*
- *death was sudden, with no previously known condition likely to cause death*
- *death was unexpected (death was not anticipated as a significant possibility in the preceding 24 hours)*
- *death occurred during sleep or in an environment in which the infant was placed to sleep, and*
- *the cause of death was not immediately obvious.*

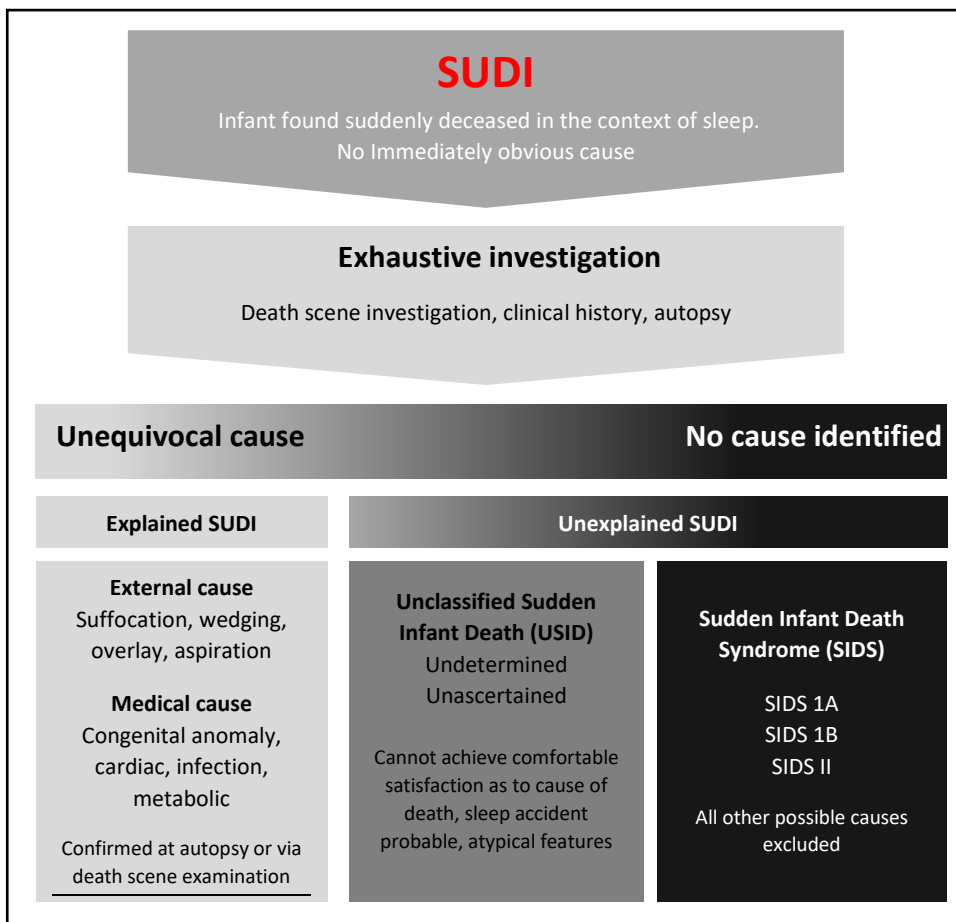
*The SUDI grouping also includes infants who were temporarily but unsuccessfully resuscitated.*

*Due to their association with sleep, SUDI are often referred to as 'sleep-related' infant deaths.<sup>7-10</sup>*

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SUDI is a descriptive term, applied at the point an infant is unexpectedly found deceased. After a thorough case investigation—including a complete autopsy, review of the clinical history and the circumstances of death—SUDI can be subdivided into two broad categories: **unexplained** and **explained** SUDI (see Figure 1).<sup>11-13</sup>



**Figure 1:** SUDI case classification process

Source: Shipstone, RS. *Extending the reach: a retrospective cohort study of Sudden Unexpected Deaths in Infancy in Queensland, Australia*. Dissertation. University of the Sunshine Coast; 2020. <https://doi.org/10.25907/00039>.

## EXPLAINED SUDI

Explained SUDI are deaths that initially appear sudden and unexpected but for which a definitive cause is later determined (either by scrutiny of the circumstances or by autopsy).<sup>11</sup>

Explained SUDI may include infections, anatomical or developmental abnormalities not recognised before death, suffocation, overlaying, entrapment, or other sleep accidents due to unsafe sleep environments. In rare cases, intentional injury may be identified.

In most cases of SUDI, it is not possible to identify a single definitive cause. In these cases, an interplay of contributory conditions and risk factors are usually evident.<sup>14</sup>

## UNEXPLAINED SUDI

Unexplained SUDI are deaths for which no cause could be determined, despite an exhaustive investigation. Such deaths are certified as Sudden Infant Death Syndrome (SIDS).

In other cases, clinical findings or environmental risk factors are present but none can be identified as the cause of death. These deaths are classified as 'undetermined', 'unascertained', or more recently, 'Unclassified Sudden Infant Death'. This is a 'grey area' classification, used when findings are insufficient to enable a specific cause of death to be identified.<sup>13, 15</sup>

### Sudden Infant Death Syndrome (SIDS)

Sudden Infant Death Syndrome (SIDS), once known as 'cot death',<sup>16, 17</sup> is a term that has been used to describe a distinctive subgroup of unexplained SUDI that share similar features, but where both death scene and pathological investigations fail to identify a definite cause of death.<sup>18, 19</sup>

SIDS is a diagnosis of exclusion.<sup>13, 20, 21</sup> This means that it can only be applied if all requisite investigations have been undertaken to look for, and exclude, all known conditions that may lead to sudden and unexpected death.

The currently accepted definition of SIDS (known as the San Diego definition, developed in 2004) defines SIDS as:

*The sudden, unexpected death of an infant under one 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.*<sup>13(p234)</sup>

The San Diego definition also stratifies SIDS into three subcategories based on the degree of certainty with which a diagnosis of SIDS can be made (see **Appendix 1**).<sup>13</sup> **Appendix 2** describes how the cause of death is determined and certified in cases of SUDI in Queensland.

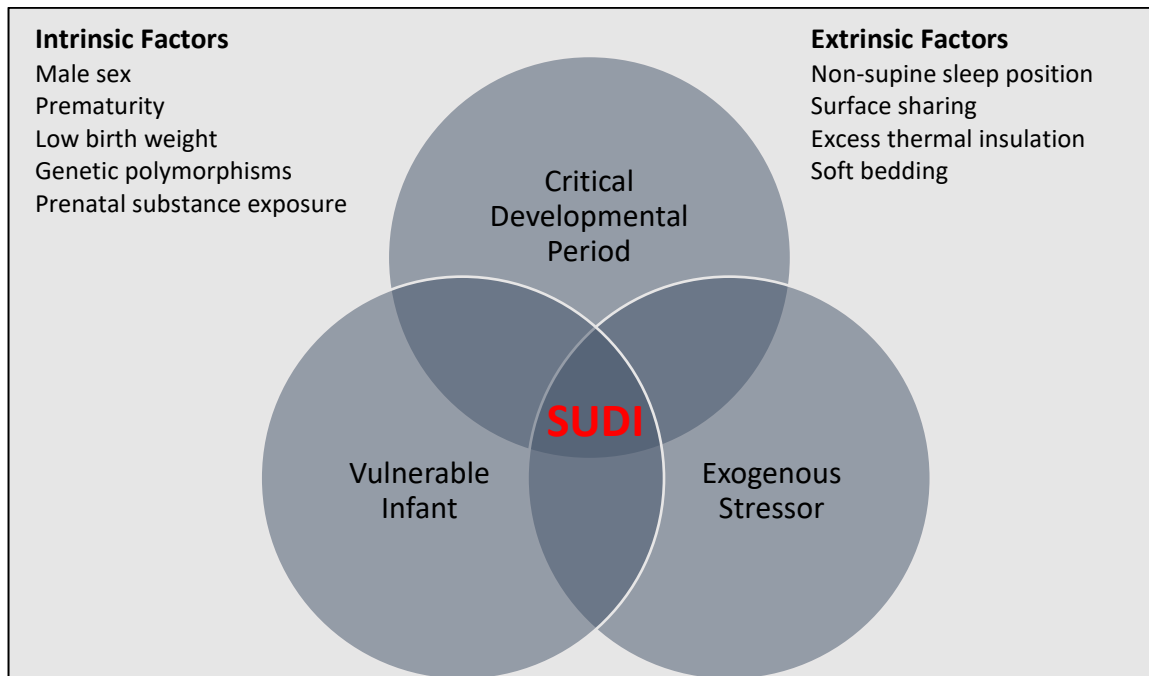
## Why do SUDI occur?

The exact cause of SUDI, including SIDS, is not known. However, there is broad consensus that most SUDI do not have a single explanatory cause. Rather, they involve the interaction of multiple factors. Each factor alone is insufficient to cause death, but when experienced in combination, death may result.

The *Triple Risk Model* is the dominant model or theory which explains this interaction (see Figure 2).

*The **Triple Risk Model** proposes that when an infant with an underlying vulnerability present at birth (such as being born pre-term or with an immature cardiorespiratory system), in a critical but unstable period in homeostatic control (i.e. the first year of life), is exposed to an exogenous stressor (such as prone sleep position) the risk of unexplained SUDI is greatest.*

In this model, risk factors can be separated into intrinsic or extrinsic factors, where intrinsic factors affect susceptibility and extrinsic factors represent physical stressors experienced around the time of death.<sup>22</sup>



**Figure 2:** Triple Risk Model for unexplained SUDI

Source: Shipstone, RS. *Extending the reach: a retrospective cohort study of Sudden Unexpected Deaths in Infancy in Queensland, Australia*. Dissertation. University of the Sunshine Coast; 2020. <https://doi.org/10.25907/00039>.

## RISK FACTORS

The risk factors for sudden infant death have been extensively researched. Epidemiological investigations have shown that many of the maternal, infant, environmental and sociodemographic risk factors for SIDS are common to the broader category of SUDI, including deaths where the cause could not be determined and fatal sleep accidents.<sup>1, 23, 24</sup>

### Infant factors

Infant factors include male sex (male infants account for around 60 per cent of SUDI);<sup>25</sup> a characteristic age distribution, with a peak between two and four months;<sup>\*26</sup> low birth weight (under 2500g); preterm birth (less than 37 weeks' gestation); intrauterine growth restriction;<sup>17, 27</sup> neonatal health problems at birth;<sup>28</sup> and a preceding respiratory or gastrointestinal illness that is not thought sufficient to cause death.<sup>15</sup>

### Parental factors

Parental factors include young maternal age; single marital status; high parity (i.e. number of births, live or still) and short interpregnancy intervals; poor perinatal care (including late booking and poor antenatal care attendance);<sup>17, 25, 29</sup> in utero or post-natal exposure to tobacco smoking;<sup>17, 27, 30-32</sup> alcohol and substance use during pregnancy<sup>33-36</sup> and after birth;<sup>27, 37</sup> and not breastfeeding.<sup>38-40</sup> A number of parental factors associated with social disadvantage have been consistently noted as increasing the risk of SUDI, including low parental education, unskilled parental occupations, unemployment, overcrowding and poverty.<sup>23, 41-43</sup>

\* In addition, few deaths are noted in the first few weeks of life or after six months of age.

## Environmental factors

Environmental factors include prone (stomach down) and side sleep position;<sup>25, 44-47</sup> sleeping in a separate room from an adult caregiver;<sup>44, 48</sup> loose and soft bedding (including pillow use);<sup>49-51</sup> head covering and excess thermal insulation;<sup>52-54</sup> and surface sharing in hazardous circumstances.<sup>55-57</sup> Hazardous circumstances for shared sleeping include sharing a sleep surface:

- with parents who smoke<sup>44, 45, 55, 56, 58, 59</sup>
- with parents affected by alcohol, substances or other sedating medication<sup>16, 56, 58, 60, 61</sup>
- when the infant is younger than three months of age<sup>44, 45, 58, 62</sup>
- when the infant was born preterm or of low birth weight<sup>44, 61</sup>
- when sleeping together with an infant on a couch or sofa.<sup>56</sup>

Infants frequently have one or more inherent characteristics (such as low birth weight and in-utero exposure to tobacco smoke) and may be exposed to sleep environments that in isolation do not present a significant risk of dying suddenly and unexpectedly. It is the cumulative effect of these factors that results in a substantially higher risk of SUDI. While SUDI, including SIDS, is not exclusive to infants with an accumulation of risk factors, research has demonstrated that over 90 per cent of SUDI have more than one modifiable behavioural risk factor.<sup>22, 60, 63</sup>

## Changes in SUDI over time

There is a large body of research which demonstrates global reductions in SUDI following the introduction of public health campaigns to reduce risk factors for sudden infant death. For example, the identification of the significant association between sudden infant death and prone sleeping position in the late 1980s and early 1990s is one of the major success stories in public health.<sup>15, 64, 65</sup> Internationally, the rate of SUDI declined by well over 50 per cent in most countries as a result of decreases in prone sleeping rates<sup>65-71</sup> following campaigns advising parents to place their infants supine to sleep (*Back to Sleep* or *Reducing the Risk*).<sup>5, 15, 65, 66, 68, 69, 72-75</sup>

In Australia, between 1990 and 2000 rates of SIDS decreased by 82 per cent.<sup>75</sup>

Despite these substantial reductions, the Queensland Family and Child Commission recorded 661 cases of SUDI in Queensland in the 16-year period between 2004 and 2019, representing nearly 10 per cent of child deaths during this period.

## CHANGES IN SUDI ACROSS SOCIAL GROUPS

Importantly, the remarkable rate reductions of the 1990s were not shared equally by all social groups. Accompanying the overall reduction in SUDI incidence, there has been a progressive widening of social inequalities, with deaths increasingly occurring in families experiencing social disadvantage.<sup>41, 56, 76</sup> Following the widespread risk-reduction campaigns, a strong independent association between SUDI and deprivation emerged. Blair et al concluded that in the United Kingdom SUDI is now “largely confined to deprived families”.<sup>77(p318)</sup> More recently, McManus et al<sup>78</sup> and Shipstone et al<sup>79</sup> noted this phenomenon in both New Zealand and Australia. Many studies have now demonstrated that there is a strong association between sudden infant death and adverse social conditions, with the more adverse the conditions the greater the risk of mortality.<sup>23, 41, 77, 80-82</sup>

The mortality reductions generated by the initial safe sleeping campaigns also did not occur commensurately in racial and ethnic minorities, including Aboriginal and Torres Strait Islander populations.<sup>66, 83-87</sup> In Australia, in the decade following the Reducing the Risk campaign, non-Indigenous SUDI rates reduced by nearly 56 per cent, while SUDI among Aboriginal and Torres Strait Islander infants reduced by 38 per cent.<sup>88</sup> A recent study demonstrated that between 2010 and 2014 Indigenous infants died suddenly and unexpectedly at a rate more

than 3.5 times that of non-Indigenous infants (see Table 1).<sup>89</sup> As is the case with many Indigenous peoples around the world, Aboriginal and Torres Strait Islander people experience disparities across all markers of disadvantage.<sup>90, 91</sup> This is directly linked to the experience of collective, historical and intergenerational trauma, which has resulted from colonisation and the associated violence and loss of culture, as well previous and recent discriminatory government policies and racism.<sup>92</sup> By virtue of the adversities experienced compared with non-Indigenous children, Aboriginal and Torres Strait Islander children are one of Queensland's most vulnerable populations.

Another recent study found the disparity between Indigenous and non-Indigenous SUDI was accounted for by surface sharing and a combination of antenatal and sociodemographic factors. These included maternal smoking during pregnancy, inadequate antenatal care, young maternal age at first birth, sole and discontinuous family structures, and outer regional and remote geographic locations.<sup>93</sup> These factors, both alone and in combination, are known to contribute to an increased infant vulnerability as well as being recognised risk factors for SUDI. A number of these factors are also associated with the multitude of stressors, challenges and disadvantage experienced by Aboriginal and Torres Strait Islander peoples.

There is broad consensus that today SUDI is primarily a condition of poor and marginalised populations, many of whom continue to cope with the legacies of trauma.<sup>77-79, 82</sup> Social inequalities, including poverty, racism and other forms of marginalisation have been identified as key drivers of the behavioural risk factors for SUDI.<sup>82</sup> Within families experiencing SUDI, it is evident that the most socially vulnerable are still lagging in their uptake of safe infant care practices. This can, at least in part, be explained by the *Inverse Equity Hypothesis*,<sup>94, 95</sup> which holds that newly introduced health interventions (such as the SUDI risk reduction campaigns of the early 1990s) will be initially adopted by the most privileged groups in a society, with much later uptake by the most deprived groups. This results in an initial widening of health inequalities, until the intervention gradually reaches the most deprived sectors. By the time this occurs, the most privileged have achieved the new minimum achievable levels of morbidity and mortality.

Within the context of SUDI, as safer sleep recommendations have generally been more widely adopted among more advantaged groups. With much later and lesser uptake by less advantaged groups, those deaths that remain are more likely to be causally related to modifiable infant care practices.

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## Key points

- *SUDI is the sudden and unexpected death of an otherwise healthy infant (aged less one year) during sleep, in which there is no immediately obvious cause of death.*
- *SUDI may be explained by a variety of causes, including infections, anatomical or developmental abnormalities, sleep accidents due to unsafe sleep environments. SUDI may also remain unexplained after investigation and be categorized as Sudden Infant Death Syndrome (SIDS).*
- *SUDI result from an interaction of multiple factors—90 per cent of SUDI have more than one modifiable behavioural risk factor.*
- *Known risk factors for SUDI include low birthweight and preterm birth; poor perinatal care; tobacco, alcohol and other substance use during pregnancy and after birth; not breastfeeding; stomach down and side sleep position; loose and soft bedding; and sharing a sleep surface with a caregiver in the context of smoking or alcohol or other substance use.*
- *The most socially vulnerable families are lagging in their uptake of safer infant care and safer sleep recommendations. As a result SUDI occur primarily in poor and marginalised populations experiencing adverse social conditions.*

- *The adversities experienced by Aboriginal and Torres Strait Islander infants contribute to a SUDI rate more 3.5 times higher than non-Indigenous infants in Queensland.*

## SUDI in the child protection population

Research has identified that infants known to the child protection system are over-represented among the cohort of infants who die suddenly and unexpectedly each year in Queensland. Between 2004 and 2019, over 24 per cent of the 661 SUDI were known to the child protection system prior to their death. While the proportion of children known to the child protection system has varied over time, currently only 7–8 per cent of Queensland children are known to the child protection system.<sup>96</sup>

The Queensland Child Death Review Board (CDRB) commenced in July 2020 with the legislated responsibility to review all deaths of children known to the child protection system. Of the deaths reviewed during its first year of operation 9 deaths were SUDI, comprising 50 per cent of infant deaths and 16 per cent of the total deaths. Forty-four per cent of SUDI deaths were of Aboriginal or Torres Strait Islander infants.\* Aboriginal and Torres Strait Islander children are significantly overrepresented among children known to the child protection system in Queensland.

Children known to the child protection system and Aboriginal and Torres Strait Islander infants are also over-represented in SUDI statistics in other Australian jurisdictions. For example, in 2019, SUDI accounted for 40 per cent of infant deaths and 20 per cent of the total deaths known to the New South Wales Department of Communities and Justice (DCJ).<sup>97†</sup> Aboriginal children accounted for 24 per cent of SUDI known to DCJ.<sup>97</sup> Given the high rate of SUDI for children known to the Queensland child protection system, there is value in generating a deeper understanding of the factors contributing to SUDI among this vulnerable cohort.

### Factors contributing to SUDI in the child protection cohort

Data from the *Queensland SUDI Study*,<sup>98</sup> a retrospective cohort study of all SUDI in Queensland occurring between 2010 and 2014, was used to examine differences in the prevalence of SUDI risk factors among families known to the child protection system compared with other families.<sup>‡</sup> Forty per cent of SUDI (91 cases) occurred in families where the infant or their siblings were known to the Queensland child protection system in the three years prior to their death.<sup>14§</sup>

Data analysis identified that the majority of SUDI in families known to the child protection system occurred in hazardous sleep environments, including surface sharing (52 per cent of families known to the child protection system, compared with 37 per cent of other families) frequently in the context of maternal smoking (52 per cent) or parental alcohol and other substance use (69 per cent). As shown in Table 2, a range of other sociodemographic and/or predisposing risk factors were also significantly more common in this vulnerable cohort, highlighting the complexity of these families' environments.

\* Child Death Review Board. *Project Outline: SUDI in vulnerable families*. Interdepartmental correspondence, 12 March 2021.

† These findings occurred in the context of a substantial increase in the number of SUDI known to the NSW child protection system in that year.

‡ The analysis below has been provided to the CDRB in confidence and is not for publication or wider distribution. It comprises preliminary data from a forthcoming analysis of SUDI in families with prior child protection involvement, by Shipstone, Young, Kearney and Thompson, with publication pending.

§ This measure differs from the criteria used by the CDRB, which considers the deaths of children known to the Queensland child protection system within the 12 months prior to their death.

**Table 1:** Prevalence of risk and sociodemographic factors in families experiencing SUDI known to the child protection system compared with other families, 2010–2014

Risk or sociodemographic factor	Known to child protection	Other families	All Qld SUDI
	%	%	%
Surface sharing	51.7	36.5	42.5
Maternal smoking during pregnancy	71.6	48.1	57.5
Exposure to environmental tobacco smoke	82.4	58.4	68.0
Alcohol or other substance use in pregnancy	42.0	7.6	20.2
Parental alcohol or substance use at time of death	59.4	31.8	42.5
Inadequate antenatal care	36.3	19.2	26.2
High parity ( $\geq 3$ live births)	47.2	12.6	26.9
Young maternal age at first birth ( $< 20$ years)	51.7	35.7	42.3
Jobless family	51.7	24.1	35.1
Domestic violence	48.4	9.5	25.0
Parental mental ill-health	59.3	17.5	34.2
Parental criminal offending	52.8	11.7	28.1
Parental victim of crime	15.4	0.7	6.5
Parent known to Child Safety or Youth Justice as child	33.0	7.3	17.5
Limited social support	41.8	8.0	21.5

Children become known to the child protection system due to concerns that they have experienced or are at risk of experiencing significant harm. It is therefore unsurprising that families who are known to the child protection system are more likely than those in the general population to have experienced these types of social vulnerabilities. However, some caution should be exercised around the interpretation of these findings, particularly regarding sociodemographic variables such as substance use, domestic and family violence, parental mental ill-health, and criminal offending. As noted by the Queensland Family and Child Commission,<sup>99</sup> by virtue of these families' involvement with the child protection system, more information is collected about the adversities which characterise their lives and it is probable that the presence of vulnerability characteristics in the general population is under-recorded.

The sociodemographic and risk factor profile found among the child protection population in the Queensland SUDI Study is consistent with two recent studies in the United Kingdom (UK). These studies investigated SUDI where children were at risk of harm due to abuse and neglect,<sup>100, 101</sup> although the presence of hazardous sleep environments involving surface sharing and substance use was substantially higher in the UK cohorts. A review of 40 cases of SUDI by the Child Safeguarding Practice Review Panel<sup>101</sup> found that a range of predisposing risk factors were common in this cohort, including sharing a sleep surface (95 per cent of cases), often in the context of parental alcohol consumption and other substance use. Cumulative neglect, domestic violence, parental mental health concerns and substance misuse were also evident in 50 per cent of the SUDI cases reported to the Panel, alongside other social factors such as deprivation, overcrowding and adverse parental childhood experiences.

Garstang's and Sidebotham's<sup>100</sup> analysis of 30 SUDI cases subject to a serious case review between 2011 and 2014 found most SUDI occurred in highly hazardous sleep environments in families well known to services, with concerns about neglect, substance abuse and poor engagement. Specifically, 89 per cent involved shared sleeping, with 81 per cent of these occurring in the context of parental alcohol and substance use. Other background risk factors included:

- parental substance misuse (67 per cent)
- parental mental ill-health (52 per cent)
- previous parental criminal conviction (48 per cent)

- domestic violence (33 per cent).

The circumstances of families known to the child protection system place them at risk not only of SUDI but also of a host of other adverse outcomes.<sup>101</sup> Many of the recognised risk factors for SUDI overlap with those for child abuse and neglect, with factors such as low income, unemployment, housing instability and parental mental ill health identified as risk factors for both maltreatment and sleep related infant deaths.<sup>101-103</sup> While SUDI are rarely directly caused by abuse or neglect, there are often concerns that the level of parental care may have been a contributory factor that put the infant at increased risk of harm.<sup>101</sup>

As noted previously, infants in the child protection population are not the only group to be disproportionately represented in SUDI. In Queensland and other jurisdictions, Aboriginal and Torres Strait Islander families, families from greater areas of socioeconomic disadvantage and families living in more remote locations experience higher rates of SUDI than other families. Around 7 per cent of SUDI in Queensland between 2004 and 2019 were of infants residing in remote or very remote areas, while only 2.6 per cent of the total Queensland population reside in these areas.<sup>96</sup> A recent study applying a 32-indicator framework to produce a measure of family-level social vulnerability found that as the level of social vulnerability increased, there was a corresponding increase in the number of known SUDI risk factors, with more vulnerable families more likely to surface share, smoke, not breastfeed and use excess bedding.<sup>79</sup> This reinforces that socially vulnerable families are either not receiving or not able to act upon current safer infant care practice recommendations.

Importantly however, the findings reported here and in previous analyses<sup>14</sup> indicate many families with no prior involvement with the child protection system that experience SUDI share risk and vulnerability characteristics similar to families within the child protection population. Because no SUDI case-control studies have been conducted in Queensland, data on the prevalence of most of these factors is generally not available for the broader population of families who do not experience a sudden infant death. Where such data does exist, however, the comparison is stark. Table 3 shows select variables from the Queensland Perinatal Data collection for 2010–2014 for SUDI families with no involvement with the child protection system and the general maternal population.

**Table 2:** Perinatal data for SUDI compared to Queensland mothers, 2010-2014

Maternal characteristics	SUDI	SUDI	Queensland
	Known to Child Safety	Other families	maternal population
	%	%	%
Maternal age < 20 years	12.1	17.5	4.9
Maternal age 20–24 years	28.5	28.5	16.8
High parity (≥ 3 live births)	47.2	12.6	10.7
Antenatal visits ≥ 5	32.6	61.1	92.3
Maternal smoking during pregnancy	71.6	48.1	15.1

The high parity (number of previous births) of mothers with prior involvement with the child protection system compared with both SUDI families who are not ‘known’ and the broader Queensland maternal population is noteworthy. This suggests that many children do not become known to the child protection system prior to birth or during early infancy, but later, as they become more visibly involved in the community, through childcare, preschool and school. For vulnerable families, adding a new child to a sibling group increases stress and may also impact their already stretched coping skills, raising community concern about the safety and wellbeing of children in the family.



It is therefore likely that at least some of the families who share similar sociodemographic characteristics to families known to the child protection system are merely not known 'yet', by virtue of the young age of the infant at the time of death. This perspective is corroborated by the Queensland Paediatric Quality Council's (QPQC) findings that in 2013, for approximately 71 per cent of infants with child protection involvement, a sibling was already known to Child Safety Services.\* The former Commission for Children and Young People and Child Guardian also previously raised concerns regarding the lack of identification of infants in families with child protection concerns, due to their very young age.<sup>104</sup>

The very limited antenatal care experienced by families with involvement with the child protection system is also significant. Antenatal care is a usual part of pregnancy for most women who give birth in Queensland. For women experiencing an uncomplicated first pregnancy, current Australian clinical guidelines recommend a minimum of 10 antenatal visits.<sup>105</sup> Women who are engaged in antenatal care are given information to support them to make informed choices about maximising the safety of the developing fetus in utero (including reducing exposure to tobacco and other drugs) as well as their infant's care after birth, including information about reducing SUDI risk.

Queensland SUDI Study data indicate that less than one-third of mothers in families known to the child protection system received half the recommended minimum number of antenatal visits. This substantially limits the ability of the healthcare system to form meaningful relationships with, and provide supportive care to, those mothers at greatest risk when they need it most. This is concerning given recent evidence that exposure to prenatal tobacco smoke and alcohol results in a 12-fold increase in SUDI (with no discernible risk from postnatal consumption).<sup>106</sup>

While interventions for at-risk families should not be limited to only those known to the child protection system, the child protection population is a readily identifiable cohort by virtue of families' involvement with statutory child protection services. Protecting children is a shared responsibility.

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## Key points

- *Infants known to the child protection system are over-represented in the SUDI population.*
- *Aboriginal and Torres Strait Islander infants are significantly overrepresented in SUDI known to the child protection system in Queensland.*
- *The presence of multiple SUDI risk factors is common in all SUDI cases including those where the infant was known to the child protection system.*
- *Factors including unemployment, substance misuse, domestic violence, mental ill-health, criminal offending and intergenerational trauma are common in families known to the child protection system who experience a SUDI.*
- *The circumstances of families known to the child protection system place them at risk not only of SUDI but also of other adverse health, development, and wellbeing outcomes.*
- *Families known to the child protection system may experience barriers to implementing SUDI risk reduction strategies. Extended health home visiting programs should be offered to families experiencing psychosocial issues to increase opportunity to access relevant parenting support and infant health services. To improve engagement with families known to the child protection system such programs and services should involve:*

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\* Infant Mortality Subcommittee, QPQC data provided for this document, June 2021.

- longer term, face-to-face delivery with high-intensity family contact and collaborative working relationships between statutory agencies (i.e., health, child protection, housing) and non-government support services
- relationship-based, continuity models characterised by positive, trusting, non-stigmatising and non-judgement partnerships and continuity of both care and carer
- family-centred approaches that acknowledge and build on family strengths and competencies, respond to the wider needs of and priorities of the family (including lack of resources, housing instability, and mental health), and increase family participation through shared decision making, and
- strong reciprocal links with other relevant services (universal and specialist).

## SUDI risk reduction in the child protection population

### Decision making and barriers to adherence to SUDI risk reduction strategies

Families with children at risk of significant harm due to maltreatment face a wide range of risks to their health, development and wellbeing, stemming from their social contexts and circumstances.<sup>101</sup> Research has demonstrated that families facing adversity, including minority populations and those experiencing financial deprivation, may experience multiple barriers adhering to SUDI risk reduction strategies and may adjust their infant care practices to accommodate their unique needs and environment.<sup>107</sup>

For example, financial hardship and transience may impact an infant's sleep location and surface—parents may not be able to afford nursery products meeting Australian standards, and overcrowding may mean an infant is unable to have its own sleep environment. The use of tobacco, alcohol and other drugs (which, in combination with surface sharing, are known to dramatically increase the risk of SUDI) may serve as important coping mechanisms for parents.<sup>108</sup> Not only do these situational risks act together to increase the risk of sudden infant death, but they may also mean that families have limited capacity to act in accordance with standard SUDI risk reduction recommendations.<sup>101</sup>

To identify effective interventions to reduce the risk of SUDI in socially vulnerable or at-risk families, it is necessary to understand parental decision-making processes regarding infant care practices, including decisions about the infant sleep environment. However, it is important to draw a distinction between families with infants at risk of abuse and neglect and families with infants at high risk of SUDI. While there is evident overlap, these two groups are not identical and should not be conflated.<sup>109</sup>

***There is currently no published literature on how families with infants at risk of harm due to abuse and neglect make decisions about infant care and safer infant sleep.***

As a result, the following review considers decision making in families with infants at high risk for SUDI. As the data presented in the previous section demonstrates, this likely includes some of the broader group of families with children at risk of harm due to abuse and neglect.

A recent review considering literature spanning the years 2000–2019 has explored how parents with infants at high risk of SUDI make decisions regarding infant care practices, specifically the infant's sleep environment.<sup>76</sup> Key findings of the review included:

- Knowledge is different from action—parents were often aware of, but did not act on, recommendations to reduce SUDI risk. Disrupted routines (such as may occur in mobile or transient families) often led to parents not following safer sleep advice either because they were unable to, or because they did not consider it relevant in their circumstances.
- Parents often treated advice as a list of options from which they could choose those best aligned with their beliefs, values and circumstances. These parents attempted to follow *most* of the risk reduction recommendations *most* of the time (rather than *all* the advice *all* the time) and saw occasional risky scenarios as acceptable.
- A strong belief in ‘maternal instinct’ and parents’ own previous experiences were identified as ‘protective factors’ that negated the need to follow safety advice.
- Concerns about the infant’s safety were also often cited as reason for hazardous sleeping practices, including surface sharing or sleeping on makeshift bedding, particularly in disrupted routines or atypical circumstances such as illness, not being in the usual place of residence, or when a parent perceived there may be a physical threat to their infant.
- Parents prioritised advice from people who they perceived to be a ‘trusted, credible source’. Particularly after receiving inconsistent advice from ‘experts’, parents were more likely to defer to an information source they perceived as more credible than statutory authorities, including partners, peers, and extended family. Previous research has demonstrated the significant influence of extended family and social networks on infant sleep practices. Without a supportive social context, stressed parents may have limited capacity to improve the infant sleep environment.
- Finally, the ‘plausibility’ of advice was an important factor. Where parents understood the mechanism of risk, they were more likely to trust and adhere to the recommendation than when they could see no logical link between advice and risk.

## IMPLICATIONS FOR THE DESIGN OF SAFER SLEEP INTERVENTIONS

Findings about decision making in families at high risk of SUDI point towards the need for a flexible and tailored approach to prevention with this group that recognises and is responsive to the reality of people’s lives.<sup>101</sup> There has traditionally been a reluctance to acknowledge the complex reality of families’ lives and to suggest strategies for reducing rather than eliminating risk.<sup>110</sup>

- Interventions should acknowledge the complexity of infant care and support parents to plan for safety at every sleep, including when routines are disrupted.<sup>109</sup>
- Models of intervention that rely solely on information-giving are unlikely to produce meaningful change for families at high risk of SUDI.<sup>109</sup> The majority of previous interventions to reduce SUDI have information-giving at their core and have been demonstrated to be largely unsuccessful in modifying behaviours in vulnerable/at-risk groups.<sup>108,111</sup>
- SUDI risk reduction conversations work best where trust and credibility has been established. A non-judgemental, culturally sensitive, personal approach that provides evidenced-based advice on which families can draw to make decisions is needed.<sup>109</sup>
- Tailoring safer sleep conversations with families’ own experiences may provide a platform for advice to be accepted.<sup>109</sup> Interventions that respond to a family’s unique circumstances, concerns and needs are more likely to be effective than a ‘one size fits all’ response that is used across all audiences.<sup>107, 109</sup>
- A clear link between recommendations and mechanisms of risk and protection should be described to reduce parental skepticism.<sup>109</sup> Previous research has demonstrated people are more likely to follow a health recommendation if they understand the rationale.<sup>108</sup> Advice is less likely to be understood and implemented if presented as a prescriptive list of dos and don’ts.<sup>112</sup>

- Given information from family and peers is prioritised, interventions that take a family approach rather than focusing solely on the mother or primary carer may be more effective. Innovations that capitalise on peer-to-peer models where information can be shared within community networks may be of use in this context.<sup>109</sup>

It is important to recognise that the points above pertain to the implications for safer sleep advice and interventions for families at high risk of SUDI. However, as the data in the previous section demonstrated, risk factors for families involved with child protection services often include ‘wicked problems’,<sup>113</sup> such as the co-occurrence of addiction, mental ill-health, housing instability and interpersonal violence, that are typically more difficult to address.

*A coordinated emphasis on reducing infant mortality by reducing tobacco and other substance use, reducing preterm birth, addressing poverty and disparities, and promoting breastfeeding is likely to be much more effective than addressing risk factors pertaining to the sleep environment in isolation. Misplaced emphasis on individual behaviour practices such as surface sharing or sleep position, rather than on these combined factors, will not be expected to lower SUDI mortality.<sup>82</sup>*

SUDI reduction approaches grounded in harm reduction principles may holistically address the familial context in which infant sleep takes place.<sup>110</sup> Harm reduction has been most often applied to risks related to tobacco, alcohol and other substance use. It is an evidence-based approach that focuses on *reducing* risk rather than *eliminating* a target behaviour.<sup>110</sup>

For example, applying a harm reduction approach to the issue of parental smoking may include offering strategies to decrease infant smoke exposure, such as encouraging parents to reduce their tobacco consumption and to smoke outside or away from their infant. An approach focused solely on smoking cessation (an elimination approach) is unlikely to be followed and may therefore miss opportunities to reduce risk. Harm reduction approaches can empower parents to make small, incremental changes to reduce risk, while helping them to understand why those changes are recommended.<sup>110</sup> In contrast, an abstinence-only approach may set the bar too high for vulnerable families, ultimately leaving them with little to no advice on how to reduce risk.

Harm reduction approaches should be:

- grounded in engaging parents in dialogue about infant sleep
- flexible
- culturally respectful
- tailored to specific contexts and address each family’s particular situation.

## Best practice interventions for SUDI risk reduction in the child protection population

Families involved with child protection services are frequently designated ‘hard to reach’ or ‘hard to engage’. Although being most in need, they tend to be the least likely to access and engage with the support offered to them by statutory agencies, due to barriers at the service, family and interpersonal level. These labels disguise the complexities these families’ lives and the factors that lead to their disengagement.<sup>114</sup>

Such terms are also problematic because they imply that the problem lies with the families themselves, rather than in the services provided for them.<sup>115</sup> There is growing consensus that rather than being ‘hard to reach’ it is more useful to think of these families as people that services find difficult to retain and engage.<sup>114, 115</sup> This involves thinking about what makes the service being offered hard for a particular family to accept. Research has

demonstrated that the success of interventions is determined as much by the way in which they are delivered as *what* is delivered, with the relationship between service provider and service users a major factor.<sup>115</sup>

Improving the uptake of SUDI risk reduction recommendations in families with children at risk of harm due to abuse and neglect is likely to reduce SUDI further. However, effective strategies to achieve this are lacking. Research regarding the interaction of child protection services and SUDI is notably sparse<sup>103, 116</sup> and tends to focus on the prevalence of SUDI among families with previous child protection service involvement,<sup>116</sup> with no SUDI risk reduction intervention studies conducted with this population. Evidence regarding how best to meet the needs of fragile and socially vulnerable families in reducing SUDI is also limited.

Family support and case management services, such as those provided by the child protection system, may allow infant sleep safety assessments to be conducted in the family home. These assessments are often limited in traditional safer sleep education strategies such as parental education classes. Where collaborative relationships have been formed, this may create an optimal opportunity for safer sleep advice to be provided in the home, in the context of non-judgmental conversations.

Internationally, the Kansas Department of Children and Families Child Protective Services has instituted a policy mandating that child protection workers assess the sleep environments of all infants under one year of age. Child protection workers undergo 'safe sleep instructor training', based on the American Academy of Pediatrics' safer sleep recommendations, to enable them to conduct these assessments.<sup>103</sup> While this has been shown to increase knowledge and understanding of SUDI risk reduction recommendations among child protection workers, behavioural changes in families who received subsequent education and advice has not been assessed. Data on rates of SUDI in that population will not be available for several years.

Due to the lack of research in this area, a recent project was undertaken in the United Kingdom to review practices and make recommendations to increase uptake of SUDI risk reduction recommendations in families with children at risk of significant harm due to maltreatment. It reviewed and synthesised the literature regarding a) interventions to reduce the risk of SUDI in families at high risk of SUDI and b) interventions to improve engagement with services in families with children at risk of abuse and neglect.<sup>\*109, 117</sup>

This emerging research suggests that to reduce SUDI in the child protection population, there is a need to move beyond a framework that views SUDI risk reduction in isolation from other risks and as solely the responsibility of a narrow range of healthcare workers. Rather, there is a need for this work to be more closely integrated with wider assessment and planning with the family to address child protection concerns.<sup>101</sup>

## SUDI RISK REDUCTION INTERVENTIONS

The UK review<sup>109</sup> found evidence that:

- **Multimodal interventions**, which provide a safe infant sleep space coupled with a comprehensive face-to-face education program (such as the Pēpi-Pod® Program in New Zealand and Queensland<sup>118-120</sup>) are effective, resulting in improvements in parental knowledge and infant care practices in vulnerable families.
- **Interventions that engage peer educators** or a process of 'paying-it-forward' (in which intervention participants agree to pass on their knowledge to the next cohort) may extend the reach of SUDI risk reduction messages into the social networks of more vulnerable groups. It is important to remain mindful that knowledge does not necessarily translate into action, so the effectiveness of these strategies should be interpreted with caution.

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\* Parental engagement was considered important as previous research has found that non-engagement with health, child protection or substance misuse services was a prominent feature in two-thirds of SUDI cases with significant child protection concerns.<sup>100, 117</sup>

- **Intensive or targeted home visiting services** improve maternal and infant health and wellbeing outcomes for families with vulnerability characteristics. They also provide support for parents and opportunities for professionals to identify risks and explore changes in both the sleep environment and infant care practices which might decrease the risk of SUDI. The most successful programs were embedded within ‘usual service provision’, were longer term—beginning during the antenatal period and continuing through the post-neonatal period—and included a clear theoretical framework.

## INTERVENTIONS TO IMPROVE ENGAGEMENT WITH SERVICES

The review found limited evidence for interventions to improve engagement in families with children at risk of harm due to maltreatment.<sup>109, 117</sup> However interventions which showed benefit involved:

- **Longer term, face-to-face programs** with high-intensity family contact and collaborative working relationships between statutory agencies (i.e. health, child protection) and non-government support services. Examples include programs that combine substance misuse treatment with parenting support. Previous research has demonstrated that for such programs to be effective they should not be mandated or involve a requirement for parental compliance and should involve more than information provision.<sup>121</sup>
- **Relationship-based, continuity models.** These models are characterised by positive, trusting, non-stigmatising and non-judgmental partnerships, and continuity of both care and carer.<sup>109</sup> The Family Care Program (Queensland Health) represents an example of one such program. This is a voluntary program with referral based on at least one of the following criteria: a high Edinburgh Postnatal Depression Scale score, the presence of domestic and family violence or financial stress, or Indigenous identification. It involves regular home visits by a child health nurse throughout an infant’s first year of life. The child health nurse works within a team that includes pediatricians and early-intervention parenting clinicians, healthy weight team, speech pathologists, psychologists, social workers and occupational therapists.
- **Family-centered approaches** that acknowledge and build on family strengths and competencies, respond to the wider needs and priorities of the family (including housing and mental health), and increase family control, though shared decision making.<sup>115</sup>
- **Strong reciprocal links** with other relevant services (universal and specialist).<sup>115</sup>

## Key points

- *There is currently no published research about how families known to the child protection system make decisions about infant care and sleep practices or effective SUDI risk reduction strategies in this population.*
- *However, research about families at high risk of SUDI, along with strategies to improve service engagement with vulnerable families, provides a useful guide for intervention in families known to the child protection system.*
- *There is a need to shift from thinking about families as ‘hard to engage’ to thinking about what makes the service being offered neither meaningful nor acceptable to families in need.*
- *There is a need for flexible and tailored approaches to SUDI prevention in the child protection population that acknowledge and address each family’s particular situation. Adopting a harm reduction rather than elimination approach is key.*
- *Reducing tobacco and other substance use and addressing the broader social and economic disparities experienced by vulnerable families is likely to be more effective in reducing SUDI mortality than addressing the sleep environment in isolation.*

- *There may be opportunities to integrate infant sleep safety assessments and safer sleep advice into existing assessment and planning with families to reduce child protection concerns.*
- *Effective programs are family-centred, involve longer term, home visiting services to improve maternal and infant health, with high intensity family contact characterised by positive, trusting, non-stigmatising and non-judgmental partnerships, continuity of both care and carer, and collaborative working relationships between statutory agencies and non-government support services.*
- *Multimodal interventions that provide a safe infant sleep space, comprehensive face to face education and engage peer educators may be effective in this population.*

## Reducing SUDI in families known to the child protection system in Queensland

This paper highlights the components needed to reduce SUDI in families known to the child protection system, identified through contemporary research literature.

Any service likely to be effective in engaging families at high risk of SUDI experiencing social vulnerability must be underpinned by:

- A **relationship-based continuity model of care**, characterised by positive, trusting, non-stigmatising and non-judgmental partnerships, and continuity of both care and carer.
- A **family-centred approach** that recognises and builds on family strengths and competencies, responds to the wider needs and priorities of the family, and increases family participation and partnership through shared decision making.
- A **harm reduction approach** (rather than risk elimination) which empowers parents to make small incremental changes to reduce risk, while helping them to understand the importance of these changes.

Optimal programs for families at high risk of SUDI in the child protection population should also include:

- Support for families to address the broader social and economic disparities experienced including, but not limited to:
  - tobacco smoking
  - alcohol and other substance misuse
  - mental ill-health
  - housing instability (including overcrowding, transience, and mobility)
  - inadequate perinatal care
  - lack of resourcing for infant care needs (such as the purchase of safe, infant-specific sleep spaces)
- Longer term, face-to-face services with high-intensity family contact and collaborative working relationships between statutory agencies (i.e. health, child protection, housing) and non-government support services, that seek to both address social and economic concerns and provide parenting support.
- The establishment of strong, reciprocal links with other relevant services.

In addition, SUDI-specific programs for families at highest risk should:

- Respond and be tailored to each family's unique circumstances, priorities, values, concerns and needs.
- They should support parents to plan for safety at every sleep, even when routines may be disrupted. This

approach would acknowledge the possibility of unplanned surface sharing, and plan with families to reduce risk if this occurs (such as removing loose bedding).

- Establish clear links between the behaviour changes proposed and the risks to infants and actively dispel myths about safe infant sleeping.
- Take a whole-of-family/social network approach whereby families are invited to identify ‘co-caregivers’—individuals who will be helping care for the infant—and encourage these people to participate in the intervention.
- Use multimodal interventions which provide a safe infant sleep space, coupled with a comprehensive face-to-face education program. This should ideally be delivered in the context of multiple home visits to reduce barriers to accessing services and increase convenience for families. This also allows coaches to observe infant sleep environment and better understand factors influencing caregiver’s decision making.

Importantly, efforts to reduce SUDI in the child protection population need to occur in the context of a system-wide approach to addressing disparities among fragile families characterised by social disadvantage and adversity.

While a Queensland-specific model for intervention for this population needs to be developed, this is beyond the scope of the current paper. However, several opportunities for further work in this area have been identified.

## Opportunities for system improvements

### FOCUS AREA ONE

*Clear and timely multi-agency, bi-directional referral pathways for families with infants and young children experiencing multiple risk factors known to place infants at risk of SUDI and coexisting child protection concerns should be developed.*

To do this, interagency collaboration is needed to identify best-practice referral pathways and service delivery for families to address both SUDI risk factors and child protection concerns and to promote statewide adoption of these models.

- A collaboration should be developed between the Department of Children, Youth Justice and Multicultural Affairs (Child Safety) and Queensland Health. This should include:
  - the Office of the Chief Nursing and Midwifery Officer (Clinical Excellence Division)
  - the Statewide Child and Youth Clinical Network
  - the Statewide Maternity and Neonatal Clinical Network
  - representatives from Primary Health Networks
  - relevant non-government service providers, and
  - consumer representatives.
- The collaboration should consider:
  - Referral pathways/protocols that are region/jurisdiction specific and reflect local knowledge, cultural backgrounds, and local support services for vulnerable families.
  - Scoping pockets of effective service provision.
  - Relationship based, family-centered, harm minimisation approaches.



- Information sharing to about child protection and health service history between agencies, in order for them to have sufficient knowledge of family dynamics and circumstances, child protection concerns, risk and protective factors to provide optimal care coordination and support to the family.
  - Timeliness of service response/engagement. Due the greatest risk of mortality occurring in early infancy, timeliness of support should be a priority.
  - Continuity of care and carer. Programs such as the Nurse Navigator Program (Queensland Health)\* have the potential to provide care coordination to complex and fragile families with coexisting health (including SUDI risk) and child protection concerns.
- The collaboration should also consider current challenges within the Queensland context including:
- Service models that are region specific (i.e. not centralised).
  - The need to co-ordinate messaging across service providers and services with different paradigms/focus.
  - The complexity of providing services that genuinely engage, are responsive to the needs of and relevant to fragile and vulnerable families known to be underserved by traditional models of care.

## FOCUS AREA TWO

*The integration of infant sleep safety assessments and the provision of safer sleep advice into existing assessment and planning with families to reduce child protection concerns should be considered the responsibility of all services involved with these families.*

- There is an identified need to move the view that SUDI risk reduction is solely the responsibility of health professionals and to more closely integrate this with assessment and planning to address child protection concerns.
- Family support and case management services, such as those provided by Child Safety, provide opportunities to conduct infant sleep safety assessments in the family home. Sleep safety assessments are often limited in traditional safer sleep education strategies such as parental education during antenatal classes. Where collaborative relationships have been formed, this may create an optimal opportunity for safer sleep advice to be provided, in the context of relationship based, non-judgmental conversations.
- There is a need for a coordinated approach with all services providing support (e.g. Child Safety, Intensive Family Support, other NGOs) so that consistent, accurate messaging is given and infant sleep practices monitored.
- Safer sleep education should be provided to all staff supporting these families. This education should include evidence-based infant settling and sleep strategies to reduce the risk of SUDI consistent with Red Nose’s safer infant sleeping public health recommendations and Queensland Health’s *Safe Infant Sleeping Clinical Guideline* (currently in consultation).

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\* The Nurse Navigator program is a statewide program designed to ensure that patients with complex health concerns access the right services in the right place at the right time and by the right healthcare professional or provider.

- All infant sleep safety assessments and safer infant sleep advice should be provided in the context of relationship-based, family-centred care, using a harm reduction approach.
- The risk of SUDI changes as an infant dynamically develops during the first year of life. Safer infant sleep conversations should occur at multiple points in time, including antenatally, prior to hospital discharge, and postnatally. Safer sleep conversations should consider major developmental milestones such as the ability to roll from front to back and change position during sleep (4–5 months), rolling supine to prone, sitting, crawling, and pulling to stand (6 months and beyond).

### FOCUS AREA THREE

*Opportunities for the statewide implementation of multimodal programs (such as the Pēpi-Pod® Program) known to assist families to implement safer infant sleep practices should be explored as an integral component of a multi-agency, targeted safer sleep initiative.*

- Queensland has led the way in the use and evaluation of the Pēpi-Pod® Program in Australia.\* <sup>119</sup> The Program has been trialed, accepted, and used appropriately by families living in Indigenous communities in Queensland and reduced the risk of SUDI in the context of surface sharing with known risk factors.
- Opportunities exist to expand the use of this program throughout the state.
- The Pēpi-Pod® Program comprises three interlinked components, including a portable sleep space, safer sleep education delivered by a health care professional, and a family commitment to use the Pēpi-Pod® as intended and to share the safe sleeping messages within their social networks.<sup>118, 119</sup>
- The Pēpi-Pod® Program has been demonstrated to function effectively as part of a maternal and child health model. Safer sleeping education is provided at several timepoints during pregnancy and after birth to provide opportunities for conversations about infant sleep environments as babies grow and develop.<sup>119</sup>
- The Program provides health professionals with a practical and innovative tool to provide a safe sleep space for families, forge connections with the family and provide support where traditional services may be avoided by these socially vulnerable families.
- A recent evaluation of the impact of the program on Queensland’s SUDI rate by the QPQC has shown some mortality benefit when the program was implemented in a coordinated way (QPQC report in preparation).
- To date, use of the Pēpi-Pod® has not been adopted into standard Queensland public postnatal care with a coordinated, statewide approach.
- It has been recommended that Queensland Pēpi-Pod® Program continue within current participating services and be expanded to include services which provide care for non-Indigenous families with identified risk factors for SUDI. These services include those providing support for smoking cessation, drug and alcohol services, intensive family support programs, and child safety.<sup>119</sup>

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\* This program has been championed by the internationally recognised work of key researchers from the University of the Sunshine Coast.<sup>119</sup>

- The QPQC and Children’s Health Queensland (CHQ) have received funding to develop and pilot a model of care for the statewide implementation of the Pēpi-Pod® Program in Queensland. This will include the development of patient selection protocols and a system of distribution and monitoring of Pēpi-Pod® use in selected birth hospitals and after birth-hospital discharge services as part of the postnatal support program. Following this a model for ongoing funding to ensure program sustainability will be required.

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# Appendix 1

## Criteria for SIDS sub-categorisation according to the San Diego definition

<b>Category IA SIDS: Classic features of SIDS present and completely documented</b>	
Category IA includes infant deaths that meet the requirements of the general definition and also all of the following requirements.	
<b>Clinical</b>	<ul style="list-style-type: none"> <li>• More than 21 days and &lt;9 months of age.</li> <li>• Normal clinical history, including term pregnancy (gestational age of ≥37 weeks).</li> <li>• Normal growth and development.</li> <li>• No similar deaths among siblings, close genetic relatives (uncles, aunts or first-degree cousins), or other infants in the custody of the same caregiver.</li> </ul>
<b>Circumstances of death</b>	<ul style="list-style-type: none"> <li>• Investigation of the various scenes where incidents leading to death might have occurred and determination that they do not provide an explanation for the death.</li> <li>• Found in a safe sleeping environment, with no evidence of accidental death.</li> </ul>
<b>Autopsy</b>	<ul style="list-style-type: none"> <li>• Absence of potentially fatal pathological findings. Minor respiratory system inflammatory infiltrates are acceptable; intrathoracic petechial haemorrhage is a supportive but not obligatory or diagnostic finding.</li> <li>• No evidence of unexplained trauma, abuse, neglect or unintentional injury.</li> <li>• No evidence of substantial thymic stress effect (thymic weight of &lt;15g and/or moderate/severe/cortical lymphocyte depletion). Occasional 'starry sky' macrophages or minor cortical depletion is acceptable.</li> <li>• Negative results of toxicologic, microbiologic, radiologic, vitreous chemistry and metabolic screening studies.</li> </ul>
<b>Category IB SIDS: Classic features of SIDS present but incompletely documented</b>	
Category IB includes infant deaths that meet the requirements of the general definition and also meet all of the criteria for Category IA except that investigation of the various scenes where incidents leading to death might have occurred was not performed and/or ≥1 of the following analyses was not performed: toxicologic, microbiologic, radiologic, vitreous chemistry or metabolic screening studies.	
<b>Category II SIDS</b>	
Category II includes infant deaths that meet Category I criteria except for ≥1 of the following.	
<b>Clinical</b>	<ul style="list-style-type: none"> <li>• Age range outside that of Category IA or IB (i.e. 0–21 days or 270 days [9 months] through to first birthday).</li> <li>• Similar deaths among siblings, close relatives or other infants in the custody of the same caregiver that are not considered suspect for infanticide or recognised genetic disorders.</li> <li>• Neonatal or perinatal conditions (e.g., those resulting from preterm birth) that have been resolved by the time of death.</li> </ul>
<b>Circumstances of Death</b>	<ul style="list-style-type: none"> <li>• Mechanical asphyxia or suffocation caused by overlaying not determined with certainty.</li> </ul>
<b>Autopsy</b>	<ul style="list-style-type: none"> <li>• Abnormal growth and development not thought to have contributed to death.</li> <li>• Marked inflammatory changes or abnormalities not sufficient to be unequivocal causes of death.</li> </ul>
<b>Unclassified Sudden Infant Death</b>	
The Unclassified category includes deaths that do not meet the criteria for Category I or II SIDS but for which alternative diagnoses of natural or unnatural conditions are equivocal, including cases in which autopsies were not performed.	

Source: adapted from Krous HF, Beckwith JB, Byard RW, et al. Sudden infant death syndrome and unclassified sudden infant deaths: a definitional and diagnostic approach. *Pediatrics*. 2004;114(1):234-8. doi:10.1542/peds.114.1.234

## Appendix 2

### Determining the cause of death in SUDI cases

Throughout Australia, all cases of SUDI are required to be reported to a Coroner. In Queensland specifically, upon finding an infant unexpectedly deceased, police officers interview the family and complete a *Police Report of Death to a Coroner* (Form 1), which includes a standard SUDI proforma. This records information on the position in which the infant was placed to sleep and found, the sleep environment (including sleep surface, surface and/or room sharing, and bedding), the infant's recent medical history, and the family's social history. It also includes a narrative description of the circumstances of death. The death scene is photographed, and in some instances, detailed witness statements are taken. A full external and internal autopsy is performed by a forensic pathologist, unless exceptional circumstances apply. The pathologist certifies the cause of death, following thorough consideration of the Form 1 and scene photographs, the infant's medical records, and the findings of the post-mortem examination.<sup>122</sup>

Despite this rigorous, standardised investigation process, pathologists in Queensland do not receive complete SUDI-relevant information in many cases, impacting their ability to reliably ascertain the cause of death.<sup>123</sup> This may result in, for example, deaths in which accidental asphyxia may have been a contributing factor (particularly when sharing a sleep surface or being placed prone (stomach down) on soft bedding) being certified as SIDS.<sup>14, 122, 124, 125</sup> This is in part because pathologists appear to prioritise post-mortem findings over information gleaned from either the death scene investigation or the clinical history when determining the cause of death. Since there are no reliable pathological markers of asphyxia in infants and young children and the autopsy findings are usually identical in cases of SIDS and suffocation,<sup>126, 127</sup> there is a tendency for pathologists to certify the death as SIDS or to attribute the cause to minor pathological findings, even in the context of a profoundly safe sleep environment. There is also evidence from previous research and pathologists' statements reported in inquest findings that death certification may be influenced by a perceived need to protect parents from stigmatising terms that imply responsibility for the death.<sup>122, 128, 129</sup> This adds to the already complex nature of sudden infant deaths, where inconsistency in cause of death classification has long been acknowledged as a "persistent and pervasive problem".<sup>130</sup> Considering sudden and unexpected infant deaths under the broader SUDI grouping is therefore useful as it facilitates the identification of factors common to a range of infant deaths, which may otherwise be missed because of the arbitrary distinction between causes of death. Furthermore, in attempting to condense contributing factors to one solitary cause of death, the ability to fully understand the importance and interplay of these factors is substantially reduced.<sup>14</sup>