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## Chapter 6 | Modifiable risk factors and the New South Wales experience

Risk factors for sudden unexpected deaths in infancy were identified in the national and international literature. The practices of parents in New South Wales in relation to these risk factors were examined among parents of infants generally and among parents of infants who died to determine the prevalence of these factors and implications for prevention.

### 6.1 Introduction

Fundamental to any attempt to reduce the incidence of SUDI in New South Wales is knowledge of associated risk factors. The prevalence of these risk factors amongst the New South Wales population and their associations with population subgroups can highlight where preventative work will have greatest effect.

A considerable body of research on risk factors for SIDS and SUDI has been developed. Little is currently known about the practices of New South Wales parents in relation to these risk factors. The identification of risk factors is dependent on the information available to epidemiologists and researchers. Efforts to identify risk factors in New South Wales have been limited by the information collected and recorded on SUDI cases (see discussion in Chapter 3).

### 6.2 Aim of this component of the study

This component of the study sought to address Research Question 4:

*What is known about modifiable risk factors for SUDI? In New South Wales, what are the parental practices in relation to these risk factors among parents of infants generally and among parents of infants who die? Are there any particular groups who engage in these risk behaviours?*

### 6.3 Risk factors

Many published studies compare the epidemiological characteristics of SIDS with non-SIDS (control) infant populations. These studies have identified socio-demographic and infant characteristics associated with SIDS and have uncovered practices and behaviours associated with a higher risk of SIDS that are amenable to change. While the research in this area has focused predominantly on SIDS, more recent research indicates that the factors associated with SUDI, whatever the cause (SIDS, explained, undetermined), show similar epidemiological profiles (Leach et al., 1999; Fleming, Blair, Platt, Smith & Chantler, 2000).

#### 6.3.1 Socio-demographic and health risk factors

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A range of socio-demographic and infant health characteristics have been found to be associated with a higher risk of SIDS and other SUDI. Among the characteristics that have repeatedly been found to be significantly associated with SIDS are: poor socio-economic status, parental unemployment, young maternal age, higher parity (number of births by

mother); neonatal health problems; and low birth weight (Bartholomew et al., 1987; Taylor & Sanderson, 1995; Fleming, Blair, Platt, Smith & Chantler, 2000; Leach et al., 1999; Arnestad, Andersen, Vege & Rognum, 2001; L'Hoir et al., 1998b; Paris, Remler & Daling, 2001; Alm, Norvenius, Wennergren, Skjaerven, Oyen, Milerad, Wennborg, Kjaerbeck, Helweg-Larsen & Irgens, 2001).

Knowledge of these risk factors can assist health professionals and public health policy makers in targeting infants and families most at risk of SUDI for provision of support, services and education aimed at preventing SUDI.

### 6.3.2 Modifiable risk factors

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Risk factors for SUDI that are potentially amenable to change provide powerful opportunities to reduce the incidence of SUDI. Throughout the past two decades strong research evidence has emerged for several risk factors relating to parental behaviour and the infant's sleep environment. The strongest and most consistent evidence for an association with SIDS has been found for:

- infant's sleeping position;
- exposure to tobacco smoke; and
- head covering.

The evidence for these and other factors are examined in more detail in the following section.

#### Infant sleep position

There is now clear evidence that the back-down position is the safest sleeping position for infants. The face-down position is a risk factor for SIDS, as is placing infants for sleep on their side, as this position is unstable and can result in the infant rolling into the face-down position.

Numerous case-control observational studies have shown that the risk of SIDS is considerably higher when infants sleep face-down. This association is maintained even after adjusting for potentially confounding variables (see Beal & Finch, 1991; Henderson-Smart et al., 1998; Gunn, Gunn & Mitchell, 2000).

The most compelling evidence that face-down sleeping is a risk factor is the significant reduction in SIDS after prevention programs were introduced. The *Reducing the Risk of SIDS* program, encouraging parents to place infant on their backs or on their sides for sleep was introduced in many countries, including Australia, in the early 1990s. Reductions in the rate of SIDS following the implementation of these programs were seen in several countries including Australia, the United States and the Netherlands. Most of the decline can be attributed to the change from the face-down sleeping position (Engelberts & de Jonge, 1990; Mitchell et al., 1992, Mitchell et al., 1994; Wigfield et al., 1992; Dwyer et al., 1995; Beal, 1995; Beal & Byard 1995; L'Hoir et al., 1998b; Skadberg et al., 1998; AAP, 2000).

Importantly, research before and after the implementation of the *Reducing the Risk of SIDS* program indicates that the face-down position remains a risk factor for SIDS. A study of 1,316 SIDS deaths occurring over 30 years (1968 to 1997) in Adelaide, South Australia, reveals that although face-down sleeping for infants in the community decreased to less than one per cent in South Australia, the majority of infants who died of SIDS were still face-down. This was true for all three decades, varying little from 83 to 86 per cent (Beal, 2000).

Numerous other studies conducted after the intervention to reduce SIDS confirmed that face-down sleeping remained a SIDS risk factor (Oyen, Markestad, Skjaerven, Irgens, Helweg-Larsen, Alm, Norvenius & Wennergren, 1997; Willinger, Hoffman, Wu, Hous, Kessler, Ward, Keens & Corwin, 1998; Brooke, Gibson, Tappin & Helen, 1997; Fleming, Blair, Platt, Smith & Chantler, 2000).

Compelling evidence for the risks associated with placing infants for sleep on their sides has emerged since campaigns advising against the face-down position (Fleming, Blair, Bacon, Bensley, Smith, Taylor, Berry, Golding & Tripp, 1996; Mitchell, Thach, Thompson & Williams, 1999). One of the major findings of the *Confidential Enquiry into Sudden Deaths of Infants* (CESDI) study, arguably the most rigorous SUDI research conducted since the intervention, showed a significantly increased risk of SUDI from side-sleeping (Fleming, Blair, Platt, Smith & Chantler, 2000). While the risk of the side-sleeping position was less than for the face-down position, it was significantly higher than for the back-down position. The risk of side-sleeping was related to the risk of the infant rolling into the face-down position.

The findings of the CESDI study are consistent with those found in the US National Infant Sleep Position Study (Willinger et al., 1998). The side-sleeping position was found to be much less stable than the face-down and back-down positions. The risk of side-placed infants rolling on to the face-down position significantly increased with age. Even at an age younger than eight weeks there was a 25 per cent chance the infant would roll from the side position, with the risk increasing to 50 per cent for infants aged 16 weeks.

Additional evidence of the risks of side-sleeping have been reported by the Nordic study (Wennergren, Alm, Oyen, Helweg-Larsen, Milerad, Skjaerven, Norvenius, Lagercrantz, Wennborg, Daltveit, Markestad & Irgens, 1997) and the New Zealand study, which concluded that infants should be placed for sleep on their back only (Mitchell, Tuohy, Brunt, Thompson, Clements, Ford & Taylor, 1997).

### **Exposure to tobacco smoke (during pregnancy and after birth)**

There have been nearly 50 studies into the relationship between smoking and SIDS. This research found not only that maternal smoking during pregnancy increased the risk of SIDS but also that postnatal exposure to tobacco smoke further increased the risk.

The finding of a significant association between exposure to tobacco smoke and SIDS has been maintained over time (before and after risk reduction campaigns) and in many countries including New Zealand, Sweden, Norway, Scotland and the United States (Mitchell et al., 1997; Oyen et al., 1997; Alm, Milerad, Wennergren, Skjaerven, Novenius, Oyen, Helweg-Larsen & Irgens, 1998; Bartholomew et al., 1987; Taylor & Sanderson, 1995). Three recent reviews summarised the relationship between smoking and SIDS (Mitchell & Milerad, 2000; Anderson & Cook, 1997; Golding, 1997). The reviews considered cohort and case-control studies, and after taking into account the methodological problems associated with these studies, all three reviews concurred on the significance of the risk for SIDS of maternal smoking during pregnancy.

The CESDI study also found a strong and independent association between smoking during pregnancy and SUDI. Furthermore, the findings demonstrate a dose-response effect, with the risk increasing with increasing cigarette consumption by the mother (Fleming, Blair, Platt, Smith & Chantler, 2000). Interestingly, the CESDI researchers found a higher prevalence of smoking

during pregnancy for all SUDI than in the control group, but a significantly higher proportion of mothers smoked during pregnancy in the SIDS group than in the explained SUDI group.

There is also some evidence of an increased risk of SIDS with postnatal exposure to smoke. In a review of the international literature, Mitchell and Milerad (2000) noted the methodological difficulties of identifying independent effects on SIDS of postnatal exposure to tobacco smoke by the mother, father and other household members. As most mothers who smoked in the postnatal period also smoked during pregnancy it was difficult to disentangle the effect of one from the other. Similarly, when examining the specific effect of the father's or other household members' smoking on the risk of SIDS it is important to control for maternal smoking. This has been problematic in many studies due to the high correlation between the mother's smoking behaviour and that of other members of the household. Nevertheless, Mitchell and Milerad (2000) concluded that there was a threefold increase in risk of SIDS with maternal smoking and evidence of a small risk of SIDS associated with other household members, particularly fathers, smoking.

The CESDI study also suggested a risk of SUDI from postnatal exposure to tobacco smoke, with the risk increasing with the number of hours infants were exposed to parental tobacco smoke (Fleming, Blair, Platt, Smith & Chantler, 2000).

### **Head coverings**

Head covering carries a high risk for SIDS and is especially associated with loose bedding such as doonas or quilts.

One of the major findings of the CESDI study was a higher risk of SIDS associated with infants found with covers over their heads (Fleming, Blair, Platt, Smith & Chantler, 2000). Doona or quilt use was more common among the SIDS group than among control infants, with a larger proportion of SIDS cases found with covers over their head during their last or reference sleep than the control group (16.2% and 2.9% respectively). In earlier analysis, the magnitude of the association between head covering and SIDS increased after other known risk factors were controlled for (Fleming et al., 1996).

These findings are consistent with previous studies showing that being found with the head covered was a strong risk factor for SIDS (Gilbert, Rudd, Berry, Fleming, Hall, White, Oreffo, James & Evans, 1992; L'Hoir, Englebets, Van Well, Bajamowski, Helweg-Larsen & Huber, 1998a). The majority of the infants that were found covered had moved down or slipped under the covers and were covered by infant doonas or quilts.

Other support for the risks associated with placing infants for sleep in circumstances where their head can become covered comes from cohort and case studies. Beal and Byard (1995) reported that 22 per cent of SIDS infants in South Australia from 1987 to 1993 were found with their head underneath bedclothes or tangled in bedclothes. The NSW Child Death Review Team has repeatedly reported on incidents of SUDI where infants were found with their heads covered by bedding (quilts, blankets or pillows) (CDRT, 2002a, 2003).

Additional support comes from physiological studies that indicate that facial obstruction by soft bedding may obstruct airways completely and lead to accidental suffocation (Galland, Peebles, Bolton & Taylor, 1994; Kemp, Kowalski, Burch, Graham & Thach, 1993).

### Other potentially modifiable factors

There is some controversy over whether sleeping together with an infant (co-sleeping) is associated with a higher risk of SIDS. (Co-sleeping is distinguished from bed-sharing, where a carer and infant share a bed for the purpose of feeding and settling.) Difficulties in assessing the risk of co-sleeping in itself arise from associations between co-sleeping and other risk factors and the difficulty of defining cause of death under these circumstances. They are often indistinguishable from suffocation due to overlying by another person in the bed and/or entrapment in bed structures and bedding (Flick, White, Vemulapalli, Stulac & Kemp, 2001; Kemp, Unger, Wilkins, Psara, Ledbetter, Graham & Thach, 2000; Beal & Byard, 1995).

A review of six case-control co-sleeping studies by Gunn et al., (2000) concluded that it was unclear whether co-sleeping was a risk factor among infants of non-smoking mothers. The analysis revealed only a small risk of SIDS from co-sleeping by a non-smoking mother, but strong evidence that co-sleeping by mothers who smoked was a major risk factor for SIDS.

A significant risk with mothers who smoke while sleeping with their infants has been found elsewhere (Blair, Fleming, Smith, Bacon, Taylor, Berry, Golding & Tripp, 1996). This study also found an increased risk among infants who shared a sofa with an adult. The authors concluded that it was not co-sleeping in itself that was hazardous but the circumstances in which it occurred. Infants who shared their parents' bed for the purpose of feeding and settling and were then put back in their own cot had no increased risk.

In a recent review of four large case-control studies examining the epidemiology of sudden unexplained infant death, co-sleeping was found to be significant: if the mother smoked, especially in the first weeks of life; if the mother consumed alcohol and the co-sleeping continued throughout the night; and for non-smoking mothers in infants younger than eight weeks (Carpenter, Irgens, Blair et al., 2004) The authors concluded that 'all-night bed-sharing should be discouraged for all mothers who smoke' (p. 190).

In general there is agreement that the potential for accidental death is increased by co-sleeping. If infants sleep with parents, safe sleeping conditions for the infant are needed (Beal & Byard, 2000; AAP, 2000; Kemp et al., 2000). Infants should sleep in the back-down position on a firm surface without pillows and immobilised in some way to prevent them sliding down under the bedclothes or becoming wedged. The American Academy of Pediatrics also suggest that parents who choose to co-sleep with their infants should not smoke or use other substances such as alcohol or drugs that may impair arousal. As an alternative to co-sleeping they suggest that parents place the infant's crib near their bed to allow for more convenient feeding and parent contact.

Another potentially modifiable risk factor identified by the CESDI study was recognition of infant illness. The study found that more SIDS than control infants were reported by parents to be in poor health. Significantly more SIDS infants were unwell and needed a doctor's assessment (10% compared with 4% for controls) or needed medical attention (5% compared with 1% for controls). The study repeatedly found that parents and health professionals underestimated the severity of illness in infants. Health professionals' failure to recognise the severity of an infant's illness was a frequent factor contributing to suboptimal care. Health professionals included general practitioners, paediatricians, health visitors, nurses, midwives and obstetricians. The authors concluded that improvement in the ability of both parents and health professionals to recognise features of illness in babies and subsequently seek or provide medical attention would reduce SUDI (Fleming, Blair, Bacon, Platt & Berry, 2000).

### 6.3.3 Summary of risk factors

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The epidemiological profile of infant deaths classified as SIDS and explained SUDI are similar to each other and differ substantially from control group infants. The common risk factors shared among SIDS and explained SUDI cases include low social status, economic disadvantage and neonatal problems in general.

Several modifiable risk factors for SUDI have been identified. The strongest evidence has been provided for:

- **sleeping position.** The back-down position is the safest sleeping position for infants. The face-down position has been repeatedly found to be strongly associated with SIDS. Side-sleeping has also been identified as a risk factor, partly because the position is unstable and infants are more likely to roll to the face-down position.
- **exposure to tobacco smoke.** Both maternal smoking during pregnancy and exposure to tobacco smoke after birth are significant risk factors for SIDS.
- **bed coverings.** Loose bedding that can cover an infant's head is associated with a high risk of SIDS. The risk is particularly associated with the use of bedding such as doonas or quilts which infants can slip under during sleep.
- **co-sleeping and smoking.** Co-sleeping can increase the risk of SIDS if the mother smokes or the caregiver shares a sofa or other inappropriate sleep environment with the infant.

## 6.4 Parental practices to modifiable risk factors evident in infant deaths

This analysis reviewed information on parental practices for the SUDI population in relation to modifiable risk factors identified from the literature.

### 6.4.1 Research method

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#### Data source

The *NSW Child Death Register* (the Register) was identified as an appropriate data source. The Register is maintained by the Child Death Review Team and contains details of all deaths of children and young people less than 18 years of age in New South Wales since 1996. The Register is based on death registration data from the NSW Registry of Births, Deaths and Marriages. Details include date of birth, date of death, date of registration of the death, cause of death noted on the death certificate, age of the child, last known residence, parents' names, place and country of birth, Aboriginal and Torres Strait Islander status and sex. For each coronial case additional information is sought.

#### Identification of cases

A death was included in this analysis if it met the definition of SUDI used by the CDRT. This definition was applied to all infant deaths registered between 1 January 2000 and 31 December 2002 that were referred to the coroner. One hundred and eighty-six deaths were identified.

### 6.4.2 Analysis

All sudden and unexpected infant deaths registered between 1 January 2000 and 31 December 2002 were analysed. The analysis of the deaths was undertaken according to the date of registration of the death. This is in line with other national data sets managed by the Australian Bureau of Statistics and National Injury Surveillance Unit.

Descriptive analyses were undertaken using the statistical package SPSS (SPSS, 1999). The analyses revealed that the information available on these deaths was incomplete and the extent of the information was variable. This limited the analyses that could be undertaken on some variables.

### 6.4.3 Results

Over the three-year period, 186 infants died suddenly and unexpectedly after being placed for sleep. Based on the available information known risk factors were evident in 86.6 per cent (161 of 186) of the deaths.

- Forty-one per cent were placed for sleep in unsafe positions (13 face-down; 63 on their side).
- Fifty-eight per cent were exposed to tobacco smoke during pregnancy and/or after birth (71 during pregnancy; 88 after birth).
- Head coverings were evident in 59.7 per cent of cases (78 had pillows; 73 had doonas, quilts and/or blankets).
- Co-sleeping in combination with smoking or substance use was evident in 25.8 per cent of deaths (24.7% were exposed to tobacco smoke during pregnancy and/or after birth; 9.7% of carers had consumed alcohol or other drugs prior to co-sleeping).

These findings concur with international literature (Leach et al., 1999).

## 6.5 Parental practices to modifiable risk factors evident in the New South Wales population

### 6.5.1 Background to parental practices analysis in the New South Wales population

This analysis reviewed information on parental practices for the New South Wales population in relation to modifiable risk factors. The *Child Health Survey 2001* (CHS) was identified as an appropriate data source for this purpose. Because the analysis was undertaken after the study took place, only three SIDS/SUDI risk factors could be examined.

### 6.5.2 Research method

#### Data source

The CHS, a cross-sectional population-based survey, was conducted by the NSW Department of Health using computer-assisted telephone interviewing (CATI). The target sample comprised at least 500 New South Wales children up to 13 years from each of the 17 health areas. One eligible child was selected from each household, using random numbers generated by the CATI system. A parent or carer of the selected child was interviewed. The survey questionnaire and a detailed description of the survey methods are published elsewhere (Centre for Epidemiology and Research, NSW Department of Health, 2002).

A total of 9,933 interviews were conducted, with a response rate of 84.9 per cent. There were 736 records relating to children less than one year of age in the CHS. Data from these records was used to investigate the social and demographic characteristics of infants and parents on three risk factors. This analysis was carried out by the Centre for Epidemiology and Research, NSW Department of Health.

### Outcome measures

The risk factors used as outcome measures for the study were:

- infant sleeping position;
- household smoking; and
- smoking during pregnancy.

Information on parental practices in relation to bed coverings could not be included in the analysis as it was not collected in the CHS and was therefore not available for analysis.

The survey question of relevance to infant sleeping position was: 'What position did you put [child] to sleep in from birth?' Responses for infant sleeping position were classified as (1) on back and (2) in other position (includes responses such as on side, on stomach, in more than one position and any other position).

The survey question of relevance to household smoking was: 'Which of the following best describes your household? Myself and others in the household smoke; I smoke, but no one else does; I don't smoke, but others in the household do'. Household smoking outcome was categorised dichotomously (yes or no).

The survey question of relevance to smoking in pregnancy was: 'When you were pregnant with [child], did you ever smoke cigarettes, cigars, pipes or other tobacco products?' Smoking in pregnancy was categorised dichotomously (yes or no).

These outcomes were examined for association with a range of social and demographic characteristics collected in the CHS and identified in the literature as associated with the outcomes:

- mother's age;
- sex of child;
- child health rating;
- parents' education;
- parents' employment status;
- country of birth of mother, father and child;
- language spoken at home;
- Aboriginal or Torres Strait Islander status of mother and father;
- contact with a baby health or early childhood nurse;
- age of first contact with baby health or early childhood nurse;
- having a personal health record;

- usual consultant for child's general health problems (local doctor, hospital or medical centre<sup>2</sup>);
- whether infant ever breastfed;
- current breastfeeding;
- total duration of breastfeeding in months;
- geographical remoteness based on the Accessibility/Remoteness Index for Australia;
- relative disadvantage based on Socio-Economic Indexes for Areas; and
- number of children in household.

### 6.5.3 Analysis

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The following analyses were carried out for each of the three risk factors on records relating to children less than one year of age.

1. The risk factors were cross-tabulated with the social and demographic characteristics previously listed.
2. Crude (unadjusted) prevalence rate ratios (PRRs) were calculated for each risk factor. The PRR is analogous in concept to relative risk, which is the incidence rate ratio used as a measure of effect in follow-up studies. As the CHS is a cross-sectional survey, it is not possible to determine cause and effect or incidence, as in a follow-up study. Instead the prevalence rates of (in this case) a risk factor for SIDS in different groups were compared. For example, if the prevalence rate of back-sleeping position for group 1 is 50 per cent and for group 2 (the reference group) is 25 per cent, then the PRR for group 1 compared to group 2 is  $50/25 = 2.0$ . In other words, the prevalence rate of back-sleeping position for group 1 is twice that of group 2. A PRR of 1.0 for group 1 means the prevalence of back back-sleeping for group 1 is the same as that of group 2. A PRR of 1.4 means the prevalence of back-sleeping position in group 1 is 40 per cent higher than in group 2, and a PRR of 0.6 means the prevalence of back-sleeping position in group 1 is 40 per cent lower than in group 2. Group 2, the reference or comparison group, has a PRR of 1.0 as it is being compared to itself.
3. Multivariate analysis was carried out for social and demographic characteristics that on crude analysis had a statistically significant association with the risk factor to obtain adjusted PRRs. Plausible interactions between the explanatory variables were assessed for effect modification.

Descriptive analyses were carried out using SAS version 8.022 (SAS Institute, 2001) and prevalence rate ratios (PRRs) were derived using Stata for Windows 3 (StataCorp, 2001).

Analyses were design-based. (In a design-based analysis, features of the survey design – sampling weights, post-stratification weight, clustering and stratification – are taken into account.) The survey sample was weighted to adjust for differences in the probabilities of selection among respondents, according to the number of eligible respondents in the household and the number of residential telephone lines for the household. Post-stratification weights were used to adjust for the differing rates of non-response among males and females, and among persons of different ages. The weights were adjusted for differences between the child's age and sex structure of the survey sample and the Australian Bureau of Statistics 2000 mid-year population estimates for each health area.

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**Notes:** 2. A medical centre is usually open long hours seven days a week and provides other services such as x-rays.

For the multivariate analysis, Cox's regression procedure was used to fit a generalised linear model to obtain adjusted prevalence rate ratios (PRRs) (Lee & Chia, 1993; Hosmer & Lemeshow, 1999). Constant follow-up time (time to event = 1) was specified and the analysis was weighted to account for sampling design effects.

Reference groups for the risk factors were selected to calculate PRRs. For the association with infant sleeping position, infants placed to sleep in other than the back-down position were made the reference group for the outcome. For household smoking those who reported no household smoking were the reference group. For smoking in pregnancy, the reference group was mothers who did not smoke during pregnancy.

In the preliminary analysis, all the variables of interest were included in the models. However a high degree of correlation was found between some socio-economic variables, so the multivariate models were built using the variables that were significant in the crude analysis. The approach to model building was to find a parsimonious model that still explained the data (Hosmer & Lemeshow, 2000). Two significance tests were applied in the model-building strategy. First was the likelihood ratio test, an overall test of the model. The second was the Wald test to assess the significance of single variables. The choice of variables to include in the models was based on the  $p = 0.05$  criterion for main effects.

### 6.5.4 Results

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#### Descriptive results

There were 736 records relating to children less than one year of age in the CHS. The socio-economic and health characteristics of the group are detailed in Appendix 6.1.

The majority of infants (62.3%) were put on their back for sleep from birth, 32.0 per cent were put on their side, 3.2 per cent were put face-down, and 2.5 per cent were put in other or multiple positions.

In 68.7 per cent of households, there was no one who smoked. In 10.5 per cent of records the mother and others in the household smoked, in 8.9 per cent only the mother smoked and in 11.8 per cent the mother did not smoke but others in the household did. The question on smoking in pregnancy was asked only when the respondent was the mother. Among mothers who were respondents, 12.8 per cent reported smoking in pregnancy. The question was not asked in 12.4 per cent of cases.

A small proportion of households (29 respondents, 3.3%) reported having all three risk factors. Households with two risk factors were also reported as follows:

- smoking in pregnancy and current household smoking (10.7% of households);
- smoking in pregnancy and infant sleeping position other than back-down (4.3% of households); and
- household smoking and infant sleeping position other than back-down (13.2% of households).

A small proportion of mothers (8.3%) did not smoke in pregnancy but reported smoking at the time of the survey. Conversely, 3.9 per cent of mothers smoked in pregnancy and reported not smoking at the time of the survey.

### Crude prevalence rate ratios

The relationship between infant sleeping position, household smoking and smoking in pregnancy and the socio-demographic characteristics was examined. Because multiple comparisons were carried out, it is likely that some associations would appear significant at  $p < 0.05$  by chance alone. For the purpose of this analysis, only associations with  $p < 0.01$  were considered significant.

On crude analysis, the following characteristics were not associated with any of the three risk factors examined: sex of child, child health rating, father's country of birth, child's country of birth, language spoken at home, Aboriginal or Torres Strait Islander father, mother's employment status, ever having had contact with a baby health or early childhood nurse, age of first contact with baby health or early childhood nurse, or having a personal health record.

Mother's and father's level of education were the only characteristics significantly associated ( $p < 0.01$ ) with all three risk factors.

### *Infants' sleeping position*

*Parent's level of education.* Mother's and father's level of education and the child's status in the household (one child or more than one child) were the only factors significantly ( $p < 0.01$ ) associated with infant sleeping position. Results for these characteristics are shown in Table 6.1.

If the mother had a tertiary degree or higher, infants were 47 per cent more likely to be put for sleep on their backs than if the mother had not completed high school (70% compared with 48%). Similarly for a father with a tertiary degree or higher, infants were 51 per cent more likely to be put for sleep on their backs (74% compared with 49%). There was no difference in the rates of back position sleeping between mothers or fathers who had completed high school and those who had not completed high school.

*Number of children in household.* Households with one child were more likely to place the child in the back-sleeping position than were households with more than one child (73% compared with 56%).

**Table 6.1**  
Crude associations  
between socio-  
demographic  
characteristics and  
infant sleeping  
position

Categorical variables	Infant sleeping position			
	On back %	Other %	Crude prevalence rate ratio	95% confidence interval
<b>Father's education</b>				
Not completed high school	49.2	50.8	1.00	
Completed high school	63.2	36.8	1.283	0.983–0.675
TAFE certificate or diploma	64.9	35.1	1.318*	1.027–1.691
Tertiary degree or higher	74.2	25.8	1.508***	1.207–1.883
<b>Mother's education</b>				
Not completed high school	48.0	52.0	1.00	
Completed high school	61.0	39.0	1.271	0.983–1.644
TAFE certificate or diploma	69.8	30.2	1.456**	1.130–1.876
Tertiary degree or higher	70.3	29.7	1.465**	1.159–1.852
<b>Number of children in household</b>				
More than one child	55.7	44.3	1.00	
One child	72.5	27.5	1.301***	1.123–1.507

*Note:*

\*  $p < 0.05$

\*\*  $p < 0.01$

\*\*\*  $p < 0.001$

### **Household smoking**

The picture for household smoking was more complex, with significant associations at  $p < 0.01$  found for numerous characteristics: mother's level of education; father's level of education; father's employment status; mother Aboriginal or Torres Strait Islander; usual consultant for child's health; ever breastfed; currently breastfed; accessibility/remoteness category; and socio-economic area category. The results of this analysis are shown in Table 6.2.

*Parents' levels of education.* The prevalence rate of household smoking decreased with increasing level of education for both mothers and fathers. Mothers or fathers who had a tertiary degree or higher reported about 80 per cent lower rates of household smoking than mothers or fathers who had not completed high school (12% compared with 56% for mothers and 11% compared with 53% for fathers). In contrast to infant sleeping position, both mothers and fathers who had completed high school were less likely to report household smoking than those who had not completed high school (31% compared with 56% for mothers and 31% compared with 53% for fathers).

*Father's employment status.* Households where the father was employed were 44 per cent less likely to report household smoking than households where the father was unemployed (28% compared with 51%).

*Aboriginal or Torres Strait Islander mother.* Households where the mother was Aboriginal or Torres Strait Islander were about twice as likely to report household smoking as households where the mother was not Aboriginal or Torres Strait Islander (61% compared with 31%).

*Usual consultant for child's health.* Respondents who usually consulted a general practitioner or local doctor for the child's health were about 42 per cent less likely to report household smoking than those who usually consulted a doctor in a medical centre (28% compared with 49%).

*Breastfeeding.* Household smoking was 58 per cent less common in households where infants had ever been breastfed than in households where they had not been breastfed (28% compared with 65%). Household smoking was 48 per cent less common in households where infants were currently being breastfed than in households where they were currently not being breastfed (21% compared with 40%).

*Accessibility/Remoteness Index for Australia category.* The prevalence rate of household smoking increased with increasing remoteness, with 30 per cent of survey respondents who lived in highly accessible areas reporting household smoking compared with 56 per cent of those in remote or very remote areas.

*Socio-Economic Index for Areas disadvantage category.* The prevalence rate of household smoking also increased with increasing social disadvantage, with 19 per cent of survey respondents who were least disadvantaged reporting household smoking compared with 40 per cent of those who were most disadvantaged.

**Table 6.2**  
Crude associations  
between socio-  
demographic  
characteristics  
and household  
smoking

Categorical variables	Household smoking			
	Yes (%)	No (%)	Crude prevalence rate ratio	95% confidence interval
<b>Father's education</b>				
Not completed high school	52.6	47.4	1.00	
Completed high school	30.8	69.2	0.587**	0.396–0.870
TAFE certificate or diploma	36.1	63.9	0.687*	0.490–0.962
Tertiary degree or higher	10.5	89.5	0.199**	0.117–0.340
<b>Mother's education</b>				
Not completed high school	55.6	44.4	1.00	
Completed high school	31.4	68.6	0.564**	0.405–0.786
TAFE certificate or diploma	30.8	69.2	0.554**	0.379–0.809
Tertiary degree or higher	12.1	87.9	0.219**	0.136–0.351
<b>Father's employment status</b>				
Unemployed	50.6	49.4	1.00	
Home duties/extended leave	56.6 <sup>a</sup>	43.4 <sup>a</sup>	1.118	0.459–2.721
Employed	27.6	72.4	0.545**	0.358–0.828
<b>Aboriginal/Torres Strait Islander mother</b>				
Yes	61.4 <sup>a</sup>	38.6 <sup>a</sup>	1.00	
No	30.5	69.5	0.496**	0.293–0.840
<b>Usual consultant for child's health</b>				
A doctor in a medical centre	48.6	51.4	1.00	
GP or local doctor	28.0	72.0	0.575**	0.417–0.794
Doctor at a hospital	41.9 <sup>a</sup>	58.1 <sup>a</sup>	0.861	0.353–2.100
Someone else	24.5	75.5	0.504*	0.255–0.998
<b>Ever breastfed</b>				
No	65.1	34.9	1.00	
Yes	27.5	72.5	0.422***	0.314–0.568
<b>Currently breastfeeding</b>				
No	39.6	60.4	1.00	
Yes	20.5	79.5	0.517***	0.378–0.707
<b>Area category</b>				
Remote/very remote	55.6	44.4	1.00	
Moderately accessible	43.4	56.6	0.782	0.432–1.413
Accessible	38.1	61.9	0.686	0.451–1.045
Highly accessible	29.7	70.3	0.535**	0.362–0.792
<b>Area socio-economic quintile</b>				
Most disadvantaged 5th quintile	40.4	59.6	1.00	
4th quintile	33.2	66.8	0.821	0.530–1.271
3rd quintile	32.5	67.5	0.804	0.532–1.214
2nd quintile	29.8	70.2	0.738	0.478–1.140
Least disadvantaged 1st quintile	19.0 <sup>a</sup>	81.0	0.470**	0.268–0.823

Note: Results shown only for factors with at least one level significant at  $p < 0.01$

<sup>a</sup> Unweighted count is less than 20

\*  $p < 0.05$

\*\*  $p < 0.01$

\*\*\*  $p < 0.001$

### **Smoking in pregnancy**

Several characteristics were found to be associated with smoking in pregnancy on crude analysis. These associations include: father's education; mother's education; father's employment status; mother's country of birth; Aboriginal or Torres Strait Islander mother; usual consultant for child's health; ever breastfed; mother's age; and total duration of breastfeeding. However, as smoking in pregnancy was reported for only 14.6 per cent of mothers, many of the associations found were in groups with fewer than 20 survey respondents. The results for significant associations ( $p < 0.01$ ) are shown in Table 6.3.

*Parent's level of education.* Mothers or fathers who had a tertiary degree or higher reported substantially lower rates of the mother smoking in pregnancy than mothers or fathers who had not completed high school (3% compared with 32% for mothers and 4% compared with 24% for fathers).

*Father's employment status.* Households where the father was employed were 68 per cent less likely to report smoking in pregnancy than households where the father was unemployed (11% compared with 33%).

*Mother's country of birth.* Smoking in pregnancy was over four times more common among Australian-born mothers than among overseas-born mothers (18% compared with 4%).

*Aboriginal or Torres Strait Islander mother.* Mothers who were Aboriginal or Torres Strait Islander were three times more likely to smoke in pregnancy compared with non-Aboriginal or Torres Strait Islander mothers (49% compared with 15%).

*Usual consultant for child's health.* Smoking in pregnancy was 54 per cent less likely when a general practitioner or local doctor was usually consulted for the child's health than when a doctor in a medical centre was usually consulted (12% compared with 26%).

*Breastfeeding.* Smoking in pregnancy was 75 per cent less common when infants had ever been breastfed than when they had not (11% compared with 43%). There was no association between smoking in pregnancy and current breastfeeding, but a significant association was found with total duration of breastfeeding. The prevalence rate of smoking in pregnancy decreased by 15 per cent for each additional month of reported duration of breastfeeding.

*Mother's age.* Of the three risk factors examined, a significant association with mother's age was found only for smoking in pregnancy, with younger mothers more likely to smoke in pregnancy than older mothers. The prevalence rate of smoking in pregnancy increased by 8 per cent for each one-year decrease in mother's age.

**Table 6.3**  
Crude associations  
between socio-  
demographic  
characteristics and  
smoking in  
pregnancy

Categorical variables	Smoking in pregnancy			
	Yes (%)	No (%)	Crude prevalence rate ratio	95% confidence interval
<b>Father's education</b>				
Not completed high school	24.3	75.7	1.00	
Completed high school	13.4 <sup>a</sup>	86.6	0.550	0.251–1.208
TAFE certificate or diploma	17.0 <sup>a</sup>	83.0	0.686	0.337–1.395
Tertiary degree or higher	3.7 <sup>a</sup>	96.3	0.144 <sup>***</sup>	0.065–0.319
<b>Mother's education</b>				
Not completed high school	32.3	67.7	1.00	
Completed high school	10.0	90.0	0.302 <sup>***</sup>	0.166–0.549
TAFE certificate or diploma	13.4 <sup>a</sup>	86.6	0.437 <sup>*</sup>	0.216–0.883
Tertiary degree or higher	3.0 <sup>a</sup>	97.0	0.089 <sup>***</sup>	0.035–0.227
<b>Father's employment status</b>				
Unemployed	33.2 <sup>a</sup>	66.8	1.00	
Home duties/extended leave	81.9 <sup>a</sup>	18.1 <sup>a</sup>	1.787	0.650–4.912
Employed	11.4	88.6	0.321 <sup>**</sup>	0.157–0.654
<b>Mother's country of birth</b>				
Other countries	4.4 <sup>a</sup>	95.6	1.00	
Australia	17.6	82.4	4.330 <sup>**</sup>	1.879–9.976
<b>Aboriginal or Torres Strait Islander mother</b>				
Yes	48.5 <sup>a</sup>	51.5 <sup>a</sup>	1.00	
No	14.5	85.5	0.314 <sup>**</sup>	0.134–0.734
<b>Usual consultant for child's health</b>				
Doctor in a medical centre	25.9	74.1	1.00	
GP or local doctor	12.0	88.0	0.458 <sup>**</sup>	0.258–0.814
Doctor at a hospital	24.6 <sup>a</sup>	75.4 <sup>a</sup>	1.084	0.307–3.832
Someone else	15.3 <sup>a</sup>	84.7	0.643	0.232–1.777
<b>Ever breastfed</b>				
No	43.3	56.7	1.00	
Yes	11.4	88.6	0.248 <sup>***</sup>	0.142–0.432
<b>Variables on a continuous scale</b>				
	Mean	Mean	Crude prevalence rate ratio	95% confidence interval
Mother's age in years	28.2	31.1	0.920 <sup>***</sup>	0.883–0.959
Total duration of breastfeeding in months	2.84	4.63	0.850 <sup>**</sup>	0.769–0.938

Note: Results shown only for factors with at least one level significant at  $p < 0.01$ .

<sup>a</sup> Unweighted count is less than 20

\*  $p < 0.05$

\*\*  $p < 0.01$

\*\*\*  $p < 0.001$

### Adjusted prevalence rate ratios

Most of the characteristics that were significant in the crude analysis were not significant after adjustment for other variables (significance was set at  $p < 0.05$  for adjusted prevalence rate ratios). The only factor that was found to have a significant association with all three risk factors was mother's level of education. No significant interactions were found.

### Infant sleeping position

For infant sleeping position, after taking other factors into account, significant associations were found with mother's level of education and the Socio-Economic Index for Areas disadvantage level. Significant associations for infant sleeping position found on multivariate analysis are shown in Table 6.4.

*Mother's level of education.* After taking other factors into account, putting a child for sleep on its back from birth was 40 to 45 per cent more likely when the mother had a TAFE certificate or diploma, or a tertiary degree or higher.

*Socio-Economic Index for Areas disadvantage category.* The prevalence rate of back-sleeping position decreased with social disadvantage. Infants in households in the least disadvantaged areas were 32 per cent more likely to be put on their backs for sleep from birth than infants in households in the most disadvantaged areas.

**Table 6.4**  
Adjusted prevalence rate ratios for characteristics associated with infant sleeping position

Significant variables	Infant back-sleeping position	
	Adjusted prevalence rate ratio	95% confidence interval
<b>Mother's education</b>		
Not completed high school	1.00	
Completed high school	1.233	0.958–1.587
TAFE certificate or diploma	1.450**	1.135–1.853
Tertiary degree or higher	1.405**	1.118–1.765
<b>Socio-Economic Index for Areas quintiles</b>		
Most disadvantaged 5th quintile	1.00	
4th quintile	1.120	0.852–1.472
3rd quintile	1.137	0.871–1.485
2nd quintile	1.115	0.847–1.469
Least disadvantaged 1st quintile	1.321*	1.013–1.722

*Note: Results shown only for factors with at least one level significant at  $p < 0.05$*

\*  $p < 0.05$

\*\*  $p < 0.01$

### Household smoking

For household smoking, after taking other factors into account, significant associations remained with mother's and father's level of education and current breastfeeding, as shown in Table 6.5.

*Parents' levels of education.* The likelihood of household smoking decreased with increasing level of education for both mothers and fathers. Mothers who had a tertiary degree or higher

reported about 50 per cent lower rates of household smoking than mothers who had not completed high school. For fathers with a tertiary degree or higher, the reduction was 68 per cent. However, the associations did not achieve statistical significance for parents who had completed high school or had a TAFE certificate or diploma.

*Current breastfeeding.* Household smoking was 31 per cent less common in households where infants were currently being breastfed than in households where they were currently not being breastfed.

**Table 6.5**  
Adjusted prevalence rate ratios for factors associated with household smoking

Household smoking		
Significant variables	Adjusted prevalence rate ratio	95% confidence interval
<b>Mother's education</b>		
Not completed high school	1.00	
Completed high school	0.755	0.540–0.055
TAFE certificate or diploma	0.794	0.521–1.211
Tertiary degree or higher	0.501**	0.299–0.837
<b>Father's education</b>		
Not completed high school	1.00	
Completed high school	0.654*	0.435–0.984
TAFE certificate or diploma	0.776	0.540–1.115
Tertiary degree or higher	0.315***	0.179–0.557
<b>Currently breastfeeding</b>		
No	1.00	
Yes	0.687*	0.506–0.934

*Note: Results shown only for factors with at least one level significant at  $p < 0.05$*

\*  $p < 0.05$

\*\*  $p < 0.01$

\*\*\*  $p < 0.001$

### Smoking in pregnancy

For smoking in pregnancy, after taking other factors into account, significant associations ( $p < 0.05$ ) were found with mother's level of education, father's employment status, and whether the child had ever been breastfed. These results are shown in Table 6.6.

*Mother's level of education.* The likelihood of smoking in pregnancy decreased with increasing level of mother's education. Mothers who had a tertiary degree were 81 per cent less likely to report smoking in pregnancy than mothers who had not completed high school.

*Father's employment status.* Households where the father was employed were 66 per cent less likely to report smoking in pregnancy than households where the father was unemployed.

*Breastfeeding.* Smoking in pregnancy was 69 per cent less likely when infants had ever been breastfed than when they had not.

**Table 6.6**  
Adjusted prevalence rate ratios for characteristics associated with smoking in pregnancy

Smoking in pregnancy		
Significant variables	Adjusted prevalence rate ratio	95% confidence interval
<b>Mother's education</b>		
Not completed high school	1.00	
Completed high school	0.454*	0.238–0.865
TAFE certificate or diploma	0.702	0.344–1.432
Tertiary degree or higher	0.178***	0.069–0.461
<b>Father's employment status</b>		
Unemployed	1.00	
Home duties or extended leave	0.807	0.308–2.117
Employed	0.341**	0.163–0.716
<b>Ever breastfed</b>		
No	1.00	
Yes	0.305***	0.173–0.536

Note: Results shown only for factors with at least one level significant at  $p < 0.05$

\*  $p < 0.05$

\*\*  $p < 0.01$

\*\*\*  $p < 0.001$

## 6.6 Discussion

The results of the analysis of the *NSW Child Death Register* indicate that in almost 90 per cent (86.6%) of SUDI cases modifiable risk factors were present including unsafe sleeping positions (40.9%), exposure to tobacco smoke during pregnancy and/or after birth (57.5%), head coverings (59.7%) and co-sleeping in combination with smoking and/or substance use (25.8%). The extent and quality of information available on these deaths limits any further comment.

Results of the *NSW Child Health Survey (CHS)* indicate that a substantial number of infants under one year of age continue to be exposed to risk factors for SIDS and SUDI. Nearly 38 per cent of infants were placed in a position other than on their backs to sleep from birth. The majority of these infants were put on their sides (32.0%), and 3.2 per cent were put face-down. In relation to other risk factors, at least one person smoked in 31.2 per cent of households, and 12.8 per cent of mothers reported that they smoked during pregnancy.

The most striking result of the analysis of the CHS is the consistent relationship between mother's level of education and risk factors for SIDS and SUDI. In both the crude and multivariate analysis the likelihood of beneficial behaviours (putting infant for sleep on their backs, no household smoking and no smoking in pregnancy) increased with increasing level of mother's education. The association was strongest with the highest level of education (tertiary degree or higher). While the associations with lower levels of education (completed high school or TAFE certificate or diploma) were for the most part not found to be statistically significant, the crude and adjusted PRRs showed a clear trend of increasing rates of beneficial behaviours with increasing levels of mother's education. This suggests that the level of statistical significance found for the relationship between the middle levels of education (completed high

school or TAFE certificate or diploma) is probably related to the sample size of the survey, rather than to the true lack of an association.

The CHS found the following factors were not associated with any of the three outcomes (infant sleeping position, household smoking, and smoking during pregnancy): sex of child, child health rating, father's country of birth, child's country of birth, language spoken at home, Aboriginal or Torres Strait Islander father, mother's employment status, ever having had contact with a baby health or early childhood nurse, age of first contact with baby health or early childhood nurse, or having a personal health record. Some of these findings may be due to the small numbers of infants reported with these characteristics. For example, only five infants were born overseas.

As the CHS is a cross-sectional data collection it is possible to describe associations, but not cause and effect. The crude PRRs indicate population subgroups that have relatively higher rates of risk factors for SUDI. Prevention programs could be targeted towards these specific sub-populations. For infant sleeping position, it would be appropriate to target parents with lower levels of education and families with more than one child. It is notable that maternal age, country of birth, Aboriginality, and living in remote areas in New South Wales were not associated with infant sleeping position.

It is also noteworthy that the majority of infants not put on their backs for sleep were put on their sides, with infants put face-down making up only 3.2 per cent of the survey sample.

The finding of an association for two socio-demographic variables – higher levels of parental education and first-time parents – with use of the back-down position are supported in other studies. A United States cohort study of over 7,000 women found face-down sleeping at one month to be associated with maternal education and parity, with mothers with less than 12 years education and more than one child more likely to engage in this risk behaviour (Lesko, Corwin, Hunt, Vezina, Mandell, McClain, Heeren, Timothy & Allen, 1998). Further evidence of an association between parents with more than one child and face-down sleeping was found in a comprehensive British study (Rose, Murphy, Macfarlane, Sefi, Shribman & Hales, 1998) and a nationally representative study conducted in Ireland (Cullen, Kiberd, McDonnell, Mehanni, Matthews & O'Regan, 2000).

The international literature has identified additional socio-demographic characteristics with high-risk sleep practices that were not identified as significant in the CHS. Numerous studies have identified young mothers as more likely than older mothers to place their infants in the face-down position (Lesko et al., 1998; Taylor & Davis, 1996; Willinger et al., 1998). Similarly, socio-economic disadvantage has been found to be associated with a higher risk of placing infants for sleep face-down (Shrivastava, Davis & Davies, 1997; Brenner, Simons-Morton, Bhaskar, Mehta, Melnick, Revenis, Berendes & Clemens, 1998). The main measure of socio-economic disadvantage used in CHS (the Socio-Economic Index for Areas) was not found to be a factor in the crude analysis of the CHS but was found to be significant in the multivariate analysis.

The results of the CHS indicate that programs aimed at reducing household smoking would best target families who are socio-economically disadvantaged, families with lower levels of parental education, where the father is unemployed, and families living in socio-economically disadvantaged areas. Mothers who are Aboriginal or Torres Strait Islander and families living in rural and remote areas should also be targeted.

In relation to interventions specifically aimed at reducing smoking in pregnancy, younger mothers, Aboriginal and Torres Strait Islander mothers, parents with lower levels of education, and families where the father is unemployed should be targeted.

The findings of a higher incidence of household smoking and smoking during pregnancy for Aboriginal and Torres Strait Islander mothers is supported by findings of other Australian studies. A Western Australian cohort study found that Aboriginal mothers were more than twice as likely to smoke and their infants were four times as likely to be exposed to smoke (Eades, Read & Bibbulung-Gnarneep Team, 1999). Furthermore, New South Wales data suggests that Aboriginal women were three times as likely to smoke at some time during their pregnancy (61%) compared with non-Aboriginal women (21%) (McDermott, Russell & Dobson, 2002). The association of household smoking and smoking in pregnancy with lower rates of infant breastfeeding found in this study suggest that families and mothers tend to engage in healthy or unhealthy behaviours in a consistent way.

The results of CHS analysis indicate that families speaking a language other than English at home or where the parents were born overseas did not engage in significantly riskier parental practices than other families. However, this does not negate the need to provide information and education campaigns on risk factors of SUDI in a range of community languages.

On multivariate analysis the relationships between smoking in pregnancy and maternal age, father's level of education, maternal country of birth and maternal Aboriginality became non-significant, but the relationship with mother's level of education and father's employment status remained significant. This indicates that the associations between smoking in pregnancy and maternal age, father's level of education, maternal country of birth and maternal Aboriginality can be largely explained by mother's level of education and father's employment. In other words, variations in the level of smoking in pregnancy among different community groups are largely explained by socio-economic factors. The conclusion is the same for infant sleeping position and household smoking.

The strength of the associations found between risk factors for SUDI and the various factors examined in this study are generally moderate. For example, mothers with a tertiary degree or higher were 51 per cent more likely (approximately one and a half times as likely) to put infants to sleep on their backs than mothers who had not completed high school. There was one quite strong association – the relationship between smoking in pregnancy and country of birth: Australian-born mothers were over four times more likely to smoke during pregnancy than overseas-born mothers. This association became non-significant on multivariate analysis, indicating that the difference between Australian-born and overseas-born mothers could be accounted for by mother's level of education and father's employment.

Considerable research has been undertaken to examine why parents refrain from or engage in modifiable risks to SIDS, in particular their choice of infant sleeping position. The findings of the studies undertaken in this area are strikingly similar despite methodological differences.

Not surprisingly, if mothers know that a particular behaviour is a risk factor for SIDS they are more likely to refrain from that behaviour (Ponsonby, Dwyer, Kasl, Couper & Cochrane, 1995). Researchers have examined differences between mothers in their knowledge of SIDS risk factors. A higher proportion of first-time mothers and mothers with higher socio-demographic status were able to recall receiving instruction on risk factors for SIDS (Colson, Stille, Payton, Bernstein & Dworkin, 2000; Rose et al., 1998).

The findings of some studies suggest that information campaigns highlighting risk factors for SIDS may not be reaching some cultural groups as effectively as others. A Queensland study found Aboriginal and Torres Strait Islander women were less able to identify a risk factor for SIDS (Douglas, Buettner & Whitehall, 2001). Factors associated with a lack of awareness of SIDS risk factors in a New Zealand study included ethnicity (Pacific Island-born, Samoan and Cook Islander), poor English language ability, low level of maternal education and not attending antenatal classes (Paterson, Tukuitonga, Butler & Williams, 2002).

Printed material was also found to be associated with use of the non face-down position, though not as strongly as the recommendations provided by health professionals (Lesko et al., 1998; Brenner et al., 1998; O'Brien, Oxman, Haynes, Davis, Fremantle & Harvey 2002; Willinger, Hoffman, Kessler & Corwin, 2000). There is some evidence to suggest that exposure to information on SIDS risk factors in different media has an additive effect (Willinger et al., 2000).

Numerous studies have pointed to the importance of the provision of information on safe sleeping by health professionals. Parents who place their infant for sleep on their backs are most likely to cite recommendations from a health professional as the primary reason for choosing that particular sleep position.

There is both theoretical and educational evidence that because people learn through observation, modelling by health care providers can be a powerful influence on behaviour (Bandura, 1986; O'Brien et al., 2002). Lesko et al., (1998) suggest that observed sleep position may modify maternal intentions and ultimately the choice of a particular sleep position. The authors conclude that health care professionals have a considerable role to play in influencing mother's knowledge of, and practice in relation to, modifiable risk factors. Likewise modelling non-smoking behaviour by health professionals in maternity hospitals may be important in modifying the smoking behaviour of carers.

While health care professionals (childbirth educators, physicians, nurses and hospital nursery staff) are in an excellent position to change parental practice, research evidence indicates that not all professionals have taken the *Reducing the Risk of SIDS* messages into their practice (Bacon & Tripp, 2000). Health professionals may know the current and major *Reducing the Risk of SIDS* recommendations but may not advise parents correctly or practise the recommendations in a hospital setting.

There is little current information on health professionals' knowledge, attitudes and practices to SIDS risk factors in New South Wales. In the one survey of all nurse unit managers in maternity hospitals in New South Wales undertaken in 2002 it was found that one third of nurses reported placing healthy term and near-term infants on their sides to sleep while in hospital, citing fear of aspiration as their primary reason (Jeffery, Reid & Kent-Biggs, 2003, cited in Jeffery, 2004).

A recent study undertaken in Queensland into the effectiveness of educational intervention in changing the attitudes of nurses and midwives to the current *Reducing the Risk of SIDS* messages and known risk factors concluded that the attitudes of nurses and midwives were inconsistent with the messages. Further, these attitudes influenced the advice that they provided to parents (Young & O'Rourke, 2003). The authors found that providing an education session and accompanying literature addressing SIDS, risk factors and the *Reducing the Risk of SIDS* messages significantly influenced several attitudes that directly related to the *Reducing*

*the Risk of SIDS* messages, with some participants changing their practice to be in line with current knowledge.

A commonly cited reason for not placing infants on their backs is parents' fear of the infant choking in this position (Willinger et al., 2000; Colson et al., 2000). For parents who have more than one child, their experience with previous children is a strong influence on their use of face-down position for subsequent infants (Lesko et al., 1998; Chessare, Hunt & Bourguigon, 1995). The main reasons parents cite for placing their infant face-down are primarily related to a belief that it is the infant's preferred sleeping position and that the infant is most settled in the face-down position (Ponsonby et al., 1995; Lesko et al., 1998; Brenner et al., 1998; Ottolini, Davis, Patel, Sachs, Gershon & Moon, 1999; Willinger et al., 2000; Gibson, Cullen, Spinner, Kate & Spitzer, 1995; Gibson, Dembofsky, Rubin & Greenspan, 2000).

The previous research provides some direction in relation to changing parents' use of high-risk sleep positions. It suggests that clear guidance to parents by health care professionals is required. To be successful this guidance must emphasise the safety of the back-down position and the instability of side-sleeping, address fears of choking and provide alternative settling techniques.

Changing parental practice in relation to maternal and household smoking may be more problematic. While the addictive nature of smoking makes it a behaviour that is resistant to change, Lumley, Oliver and Waters (2002) demonstrated that interventions for smoking cessation during pregnancy are successful.

The findings of the CHS and what is known from the international literature on risk factors, parents' knowledge, attitudes and practice in relation to modifiable risk factors provide information to further reduce the incidence of SUDI. Clear information on risk factors to parents and health professionals is required. Furthermore, the findings suggest that subgroups of the population may need specifically targeted prevention and information campaigns on risk factors.

Sudden unexpected deaths in infancy that resulted from assault or neglect or that occurred in circumstances suspicious of assault and neglect are examined to identify the factors associated with, and the circumstances surrounding, the deaths; the extent of contact the infants' families had with human service agencies, the coronial and criminal outcomes and avenues for prevention.

### 7.1 Introduction

The Child Death Review Team had a unique and specialised function in relation to deaths due to abuse or neglect. The Team was mandated to identify the deaths of children that were due to or suspicious of abuse or neglect and undertook a detailed review of the information concerning these deaths, with a view to prevention. This function was transferred to the NSW Ombudsman in December 2002.

As the reviews are completed, the findings are usually reported in the Annual Reports of the CDRT. For the 2003 year the Team decided to report incidents of SUDI that occurred in circumstances of abuse or neglect within this study. In doing so an important part of the picture of SUDI in New South Wales is presented.

Research undertaken into the fatal assault of children and young people in New South Wales identified infants as having the highest rate of fatal assault, with 5.8 deaths per 100,000 population for this age group. By comparison the rate of fatal assault for all children 0 to 17 years inclusive in New South Wales is just over 1 death per 100,000 (CDRT, 2004b). Across Australia, children under one year of age are also reported to be at greatest risk of fatal assault; for females the rate of fatal assault in infancy is the highest across their entire life course (Mouzos, 2002; cited in CDRT, 2002b).

The Child Death Review Team's research (CDRT, 2002b) examining the deaths of all children who died from fatal assault established that 18 of the 60 assault deaths identified over a three-and-a-half-year period involved infants less than one year of age. Thirteen of these 18 fatalities were associated with non-accidental injury and five with the mental illness of the mother.

This pattern is reflected in international studies. For instance, in England and Wales a person is four times more likely to be a victim of homicide in the first year of life than at any subsequent age (Bacon & Tripp, 2000).

Fatal non-accidental infant deaths among SUDI cases have been examined in two large and reliable studies undertaken in the United Kingdom (Leach et al., 1999; Bacon & Tripp, 2000). Leach et al., (1999) concluded that fatal non-accidental injury occurred in 4.5 per cent of all incidents of SUDI. Non-accidental injury as a cause of explained death was second only to infection and equal to or greater than cardiovascular anomalies in contribution.

Bacon and Tripp (2000) found that of the 417 SUDI cases studied, there was suggestion of maltreatment in 17 per cent, ranging from criminal prosecution to suspicion by an expert group. Overall there was concern of maltreatment, extending from deliberate action such as smothering to negligence and extremely poor care, in 14.5 per cent of SIDS and 9.9 per cent of explained SUDI.

The features that raise concern of maltreatment in the history and initial examination, summarised from three recent sources, include:

- a family with previous unexplained infant death or non-accidental injuries.
- a parent with a history of being assaulted as a child followed by personality disorder and self-harm.
- a baby with previous injuries or episodes of sudden illness, such as apnoeic attacks that were inadequately explained and occurred in the presence of the same carer.
- death outside the usual age range for SIDS, although unnatural deaths are most common in children younger than eight months.
- death in the afternoon or evening, after recent admission to hospital, or where the dead infant came from a family in which a previous child had died unexpectedly, especially if under the care of the same person (Reece, 1993; Bacon & Tripp, 2000; AAP, 2001).

In addition, the Child Death Review Team (2002b) identified the following associations: family violence; mental health; substance use; suicidal mother; financial difficulty; and criminal arrest.

Infant deaths are difficult situations for both investigating police and forensic pathologists. In its study into fatal assault the Team found no recorded witnesses to any fatal assault that occurred in the infant's home (CDRT, 2002b).

Forensic pathologists face challenges in establishing cause of death as it is challenging to distinguish at autopsy between SIDS and accidental or deliberate asphyxiation with a soft object (Valdes-Dapena, 1992, cited in Levene & Bacon, 2004). Deliberate suffocation may leave no external signs and no clear post-mortem evidence. Eliciting a history of possible intentional suffocation in particular circumstances is essential (AAP, 2001).

To establish fatal assault as the cause for apparent SUDI and determine incidents of SUDI associated with fatal neglect, it is essential to undertake a death scene investigation, a careful complete autopsy, and a case review of all available medical, hospital, social service information including mental health, child protection and social circumstances (AAP, 2001).

## 7.2 Aim of this component of the study

This component of the study sought to address Research Question 5:

*What is known about SUDI cases where the infants have died as a result of assault or neglect or in suspicious circumstances?*

## 7.3 Research method

### Access to data

Section 45T of the *Commission for Children and Young People Act 1998* imposes a duty on departments, agencies and individuals to provide the Team with 'full and unrestricted access'

to records that the Team reasonably requires for the purpose of exercising its functions. The institutions and organisations affected include: all government departments, statutory bodies and local authorities; the Commissioner of Police; the State Coroner; medical practitioners or health care professionals or heads of bodies that deliver health services to children; persons who, or the heads of bodies that, deliver welfare services to children (including family support services, children's services, foster care or residential out-of-home care, and disability services); and principals of non-government schools (within the meaning of the *Education Act 1990*).

### The Child Death Register

Since 1996 the NSW Child Death Review Team has maintained a *Child Death Register* (the Register) of all deaths of children and young people less than 18 years of age who die in New South Wales. The Register is based on death registration data from the NSW Registry of Births, Deaths and Marriages. Information includes date of birth, date of death, date of registration of the death, cause of death noted on the death certificate, age of the child, last known residence, parents' names, place and country of birth, Aboriginal and Torres Strait Islander status and sex.

For each coronial case additional information is sought, including: the *Police Report of Death to Coroner* (P79A, which includes a narrative of the circumstances of the death); the *Death Scene Investigation Checklist – Sudden Infant Death* (P534, completed by police for cases suspected of SIDS); and a final post-mortem report (including autopsy, pathology and toxicology findings).

### Identification of cases for study

**Identifying cases of sudden and unexpected death in infancy.** A death was included in this study if it met the Child Death Review Team's definition for SUDI. This definition was applied to all infant deaths registered between 1 January 2000 and 31 December 2002 that were referred to the Coroner. One hundred and eighty six deaths were identified.

**Identifying cases of assault or neglect or suspicious of assault or neglect.** The CDRT identified and reviewed child deaths caused by assault or neglect or deaths that were suspicious of assault or neglect from January 1996 until December 2002. To assist with accuracy, the Team developed its own set of definitions (see Appendix 7.1) and screening procedures.

The screening procedure consisted of two stages:

1. initial screening of cases; and
2. further screening of cases with additional information.

Screening was undertaken by representatives of the CDRT including a paediatrician and others with child protection experience. To inform the screening decision information was sought from the Department of Housing and NSW Health. Further information was obtained from NSW Police, Department of Community Services and the NSW Coroner. Full details of the screening process can be found in Appendix 7.2.

Of the 186 incidents of SUDI, 12 deaths were identified during the screening process as due to assault or neglect. Based on the information available it was not possible to determine with any confidence whether a further 50 deaths were due to assault or neglect or not. In these 50 cases there was some information to raise concern of possible maltreatment but not sufficient

evidence to indicate that assault or neglect caused the death. Similar difficulties arising from a lack of adequate information have also been identified as a factor in the determination of cases of maltreatment in other studies (Department of Health, 1996). Notwithstanding data inadequacies, for the remaining 124 cases the information available did not raise concern of maltreatment.

## **7.4 Analysis**

### **Analysis period**

All sudden unexpected infant deaths registered between 1 January 2000 and 31 December 2002 were analysed. (Nineteen cases previously reviewed and reported by the Team were included.) The analysis of the deaths was undertaken according to the date of registration of the death. This is in line with other national data sets managed by the Australian Bureau of Statistics and National Injury Surveillance Unit.

### **Case review tool**

The case review tool developed by the Team to review assault and neglect deaths or those that occurred in suspicious circumstances was modified to include information specific to sudden unexpected infant deaths. The tool consisted of variables clustered around the following domains: demographics; circumstances of the death; individual circumstances; family background; prior agency involvement; and experiences related to childcare, education and employment. This tool was completed for each case by child protection consultants by means of a case file review of government records obtained from NSW Police, the NSW Coroner, NSW Health, the Department of Community Services and the Department of Housing.

Descriptive analyses were undertaken using the statistical package SPSS (SPSS, 1999). An overall profile was created of the infants who died as a result of assault or neglect and those who died in circumstances where no clear determination was possible.

A logistic regression model was created to examine factors which may differentiate the 50 deaths where no clear determination was possible from those where there was clearly no assault or neglect. Logistic regression is a technique used to examine which variables are useful in predicting an outcome (SPSS, 1999). Several variables of interest could not be examined because of the severe limitations of the information available (for example, carer substance use) and the rarity of some events (for example, previous incident of SUDI in the family). The variables examined were:

- infant age at death;
- vulnerability to harm;
- domestic violence;
- diagnosed mental health conditions of carers; and
- adult offending by carers.

### **Methodological limitations and cautions**

The Register provides information on all child deaths registered in New South Wales. As with all data sets that rely on administrative data sources, the extent of information contained in the records was highly variable. In addition, there may be omissions of information and a small

number of errors. The validity and reliability of the information recorded for the Register has not been formally verified. For all coronial cases the reliability and validity of the data is improved by access to several different data sources.

All cases were reviewed by representatives of the Team who used available information to arrive at a shared opinion as to whether a death was caused by assault or neglect. However, without a coronial or criminal finding of fatal assault the Team's conclusions are subjective judgements.

## 7.5 Results

Over the three-year period from January 2000 to December 2002, 186 infants died suddenly and unexpectedly after being placed for sleep.

Table 7.1 shows that 12 of these infants died as a result of assault (3) or neglect (9). No clear determination was possible for 50 infant deaths.

**Table 7.1**  
Category of death

Category	Total	
	n	%
Not assault or neglect	124	66.7
No clear determination possible	50	26.9
Assault	3	1.6
Neglect	9	4.8
<b>Total</b>	<b>186</b>	<b>100.0</b>

### Fatal assault

Deaths from fatal assault were rare among the 186 infant deaths during the three-year period from January 2000 to December 2002: three infants died as a result of assault. The small number of deaths and the absence of available data limit the conclusions that can be drawn about these deaths.

The three causes of death as determined by forensic pathologists were: undetermined; multiple injuries; and consistent with smothering.

The three infants (two males, one female) were aged six months, seven months and 10 months. Two were living with both biological parents and one was living with one biological parent. Perpetrators were identified in two cases: the biological mother in one case and the mother's de facto in the second case. In the third case no perpetrator was identified.

All three infant deaths were categorised by the CDRT<sup>3</sup> as non-accidental injury, meaning that the injuries resulted from either a series of assaults or one fatal assault. In one case, a carer's mental health condition may also have played a role.

All three families had experienced disadvantage in relation to health and well-being, violence, crime or social and economic factors. These were parental mental health problems (1 family),

**Notes:** 3. The *Fatal Assault of Children and Young People* report (CDRT, 2002), identified four categories of fatal assault: non-accidental injuries, assaults by parents affected by mental illness, assaults related to family breakdown, and killings of teenagers.

suicide attempts (2 families), parental substance use (2 families), parental criminal behaviour (3 families), domestic violence (2 families) and financial difficulties (2 families). Carers in two families had also been victims of child abuse and neglect.

All three infants came from families that had prior agency involvement. Agencies involved with the families were the Department of Community Services (3), NSW Police (3), NSW Health (3), the Department of Housing (3), the Department of Corrective Services (1), and private health practitioners (3). Extensive involvement with the Department of Community Services, NSW Police and NSW Health was evident for all three families.

The three infants had all been reported to be at risk of harm to the Department of Community Services. One infant had been the subject of four prior reports, one infant had two prior reports and one infant had one prior report—a total of seven reports. Assessments and investigations commenced for six of the seven reports made. Siblings of the infant had also been reported to the Department of Community Services in all three families.

In responding to two of the three families, workers appeared to underestimate the level of risk the infant was exposed to while living in their family environment. The high level of risk associated with clusters of multiple indicators was not recognised, and the two infants remained in high-risk situations. Intervention in two cases was crisis-driven rather than proactive, and there appeared to be limited understanding of how to intervene to modify or lower risk.

NSW Health was also involved with all three families. In two cases, in different Area Health Services, the infant was taken to the same Hospital Emergency Department on repeated occasions.

Health professionals within the NSW Health system appeared to underestimate the risk for infants in dangerous family environments and did not recognise escalating presentations as indicative of increasing risk.

NSW Police were also involved with all three families. There was evidence that NSW Police reported risk of harm to the Department of Community Services appropriately.

A coordinated interagency approach was lacking in all three cases. In two cases, a coordinated interagency approach may have assisted in identifying the high risk present by combining the information held by each agency. While individual services were well delivered at times, they lacked coordination. In the third case, while an interagency approach may have resulted in a greater understanding of the dynamics operating in the family, it may not have prevented the infant's death.

Coronial proceedings commenced for all three cases. In one case an inquest was held and a finding of the cause of death as 'Not determined' was given. In two cases the inquest was terminated and charges were laid. In one case the infant's mother's de facto was charged with murder; he was found guilty of manslaughter and sentenced to 11 years imprisonment. In the second case, the infant's mother, who was found to be suffering from the effects of postnatal depression at the time of the death, was charged with murder. She was sentenced to four years supervision.

### Fatal neglect

Nine (4.8%) of the 186 infants died as a result of neglect during the three-year period January 2000 to December 2002. There were five males and four females, and the age of infants ranged from nine days to seven months. One of the nine infants was Aboriginal. The small number of deaths and the absence of available data for some variables limit the conclusions that can be drawn about these deaths.

The causes of death as determined by forensic pathologists were sudden infant death syndrome (2); sudden infant death syndrome associated with co-sleeping (1); undetermined (3); positional asphyxia (1); combined effects of positional asphyxia associated with co-sleeping and acute on-chronic aspiration (1); and bronchopneumonia (1).

The nine infant deaths assessed as fatal neglect showed characteristics similar to the category of inadequate supervision by a carer previously identified by the CDRT.<sup>4</sup> They involved impaired parenting capacity as a result of drugs, alcohol, mental illness, physical illness, immaturity or impaired intellectual ability.

Five infants died in circumstances in which their carer or carers were affected by alcohol and/or drugs. Three infants died when co-sleeping with parents who were affected by alcohol and/or drugs. (Co-sleeping is distinguished from bed-sharing. The term bed-sharing is used to describe circumstances where a carer and infant share a bed for the purpose of feeding and settling.) A fourth infant was found dead after not having been fed or checked for 14 hours.

Four infants died in diverse circumstances when carers made inappropriate decisions relating to their care. One infant died from accidental suffocation while co-sleeping with a parent who was a heavy smoker. A second infant died as a result of accidental hanging after being placed for sleep in a stroller without the restraint secured. The third infant died as a result of undiagnosed bronchopneumonia. The infant's carer had recently experienced a stressful life event and may not have recognised the signs of illness in the infant. The fourth infant died after being placed face-down for sleep in a cot. The infant's carers had previously been advised that this was not a safe position for the infant.

**Family circumstances.** Five of the nine infants were living with both biological parents and four were living with one biological parent. The ages of the primary carer ranged from 16 to 32 years (mean 24.4, SD 5.7). The secondary carers were typically older, with ages ranging from 24 to 41 years (mean 30.1, SD 6.6).

The fatal neglect of these nine infants all occurred in the context of family stress. All nine families experienced disadvantage: problems with health and well-being, violence, crime, or social or economic disadvantage. There were parental mental health problems (4), parental physical health problems (1), parental substance use (7), domestic violence (8), parental criminal behaviour (7), changes in family composition (1), financial difficulties (2) and accommodation difficulties (6). One carer had been the victim of child abuse and neglect.

The stressors experienced by these carers may have affected the standard of care they were able to provide for these infants. Accommodation difficulties, mental health problems, and drug and alcohol use were identified as impacting on their parenting capacity.

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**Notes:** 4. The *Fatal Assault and Neglect of Children and Young People* report (CDRT, 2003), identified three categories of neglect deaths; deaths due to inadequate supervision by a carer, negligent driving by a carer, and failure by a carer to provide medical care.

Domestic violence was identified in eight of the nine families. Two carers had recently moved to escape domestic violence, with one carer returning to a violent situation shortly before the infant's death. While ongoing domestic violence was not directly linked to the deaths of these nine infants, it may have affected the capacity of carers to attend to the needs of their infant.

Accommodation difficulties were noted for six of the nine families. Issues included the poor physical state of homes, inadequate heating, and overcrowding. Two families were living in Department of Housing accommodation, two families were living in caravans, one family was living with extended family and one family was staying temporarily with friends. Three families had recently moved, with one family having moved several times within a few months. Two families experienced financial difficulties. Accommodation and financial difficulties may have limited carers' options in providing safe sleeping environments for infants; four infants died when co-sleeping with adults and one died after being placed for sleep in a pram.

A history of substance use was noted in seven of the nine families: in three families use of both alcohol and drugs was noted; in three families use of alcohol only; and in one family use of drugs only. Drugs used by carers included marijuana, amphetamines and methadone. The deaths of five of the nine infants occurred while carers were affected by alcohol and/or drugs.

Mental health problems had been diagnosed in carers in four of the nine families. Diagnoses included depression (2); post-traumatic stress disorder (1); and previous episodes of paranoid delusions (1). Postnatal depression was suspected but not diagnosed in one additional carer.

Eight of the nine families experienced three or more stress factors. For example, in five families issues of substance use were present together with domestic violence and adult offending. In four of these families, problems were further exacerbated by mental health problems (2) and/or accommodation and financial difficulties (3). Greater understanding of how these multiple factors interact is needed.

**Agency involvement.** The nine infants came from families that had prior agency involvement. The agencies involved with the families were NSW Health (9), NSW Police (6), the Department of Community Services (5), the Department of Housing (3) and non-government organisations (2).

Three of the nine infants had been reported as at risk of harm to the Department of Community Services. In total, the infants had been the subject of seven reports (one, two and four reports respectively). Assessments and investigations commenced for five of the seven reports.

Responses to these three infants and their families showed a tendency to minimise the risk factors present in the infant's family environment. The Department of Community Services failed to undertake full risk assessments and relied on other agencies to monitor the infant's situation. One case was closed after an unsuccessful home visit with questions raised concerning the mother's capacity to parent not addressed.

While infants had not been reported at risk of harm to the Department of Community Services in two families, these families had been involved with the Department prior to the infant's birth as a result of reports regarding siblings. In one family no risk assessment was undertaken following concerns expressed by a health professional providing services to the mother. The Department of Community Services had prior knowledge of the family removing other children from the mother's care before the infant's birth.

In two cases where neither infants nor their siblings had been reported to the Department of Community Services, information on file indicated that there was sufficient information for a report to be made by police or health professionals.

NSW Police were involved with six of the families. While there was evidence of police fulfilling their mandatory reporting obligations in some cases, there was also evidence of failure to recognise and report serious and unstable situations to the Department of Community Services in three cases. Failure to report these infants highlights missed opportunities for intervention with families that were clearly experiencing difficulties.

NSW Health was involved with the nine families. Infants and their families attend health services for a range of reasons often presenting opportunities for health professionals to identify infants who may be at risk and to take appropriate action. There was evidence that health practitioners failed to identify risk when infants were born and to report concerns for the infant to the Department of Community Services.

In one case, the brief psycho-social assessment undertaken in hospital failed to identify the impact that the mother's circumstances may have had on her capacity to care for her infant. Following discharge from hospital, there was evidence in three cases that health professionals providing home-visiting services to the mother failed to recognise or report concerns of increasing violence and concerns about the infant's failure to gain weight to the Department of Community Services.

In cases where multiple agencies were involved, there was little evidence of a coordinated interagency response to these families. Such an approach may have identified the multiple risk factors present in some of these families and possibly led to increased intervention.

Inquests were dispensed with by coroners in eight of the nine cases. In the one case where an inquest was held the cause of death remained undetermined.

### **No clear determination possible**

In just over a quarter of the 186 infant deaths (50, 26.9%), it was not possible to determine whether the death was due to assault or neglect or not. The information available on these infants was insufficient to raise concern of possible maltreatment but not sufficient for the Team to make a clear determination.

The infants ranged in age from less than one week to nine months, with deaths peaking at two months of age (30 were male; 20 were female). Thirteen of the infants were identified as Aboriginal or Torres Strait Islander. Seven infants were born to mothers who were born outside Australia.

Almost all of the deaths occurred within the infant's home (45; 90.0%). One death occurred in a foster home, one in a women's and children's refuge, one in institutional care and one in the home of relatives.

Table 7.2 shows the causes of death for the 50 infants as determined by forensic pathologists. A diagnosis of SIDS was given in 26 cases (52.0%); 19 deaths were identified as due to undetermined causes (38.0%) and in five cases a specified cause was given.

**Table 7.2**  
Cause of death

	n	%
Sudden infant death syndrome <sup>a</sup>	26	52.0
Undetermined	19	38.0
Diseases and morbid conditions	3	6.0
External causes of injury	1	2.0
Injury	1	2.0
<b>Total</b>	<b>50</b>	<b>100.0</b>

*Note: a Six cases were diagnosed as SIDS associated with co-sleeping*

An analysis was undertaken of these 50 infant deaths to identify the presence of factors identified in the literature as raising concern of maltreatment (Reece, 1993; Bacon & Tripp, 2000; AAP, 2001; Block, 2002; Levene & Bacon, 2003; CDRT, 2002b, 2003). Due to the lack of information available on these deaths only some of these factors could be examined and of those, fewer still could be examined in detail.

**Death outside the usual age range for SIDS.** Nine of the 50 infants were outside the usual age range (eight were under one month and one was over six months).

**Previous unexplained infant death.** A previous incident of sudden unexpected infant death was positively identified in the immediate family in two cases. In a third case, there was such an incident in the extended family living in the same location. Previous research has identified that a previous sudden unexpected infant death can arise from natural causes (Levene & Bacon, 2004).

**Recent hospital attendance or multiple presentations to hospital.** Eleven of the 50 infants had presented to hospital following birth. Reasons included failure to thrive (2); episodes of apnoea (2); bronchiolitis (1) or bronchitis (2); fever, nausea, vomiting and/or constipation (2); urinary tract infection (1); flu symptoms (1); and following a fall (1). Multiple presentations to hospital were seen in three cases. A further two infants died within 48 hours of being discharged from hospital following birth.

**Signs of injury and physical signs of neglect at autopsy.** Signs of injury were present at autopsy in five of the 50 infants. Signs of injury included: recent and healing fractures of ribs and arms; subarachnoid, subdural and retinal haemorrhages; detached retinas; bruising to the head, trunk, and arms or legs; and injuries to the frenulum. Signs of neglect were present at autopsy in nine of the infants; four infants showed evidence of failure to thrive; four infants had failed to gain weight appropriately; and one infant appeared malnourished.

**Vulnerability of the infant.** There was no accepted measure of vulnerability to death known to the Team. As a result, the Team employed a proxy measure of vulnerability. An infant was considered vulnerable if any child of the family had been reported to the Department of Community Services as at risk of harm prior to the infant's death. Using this measure 35 infants (70.0%) were assessed as vulnerable.

**Previous offending behaviour by carer.** Carers in 30 families (60.0%) had a record of offending behaviour as an adult. Charges related to theft, offences against the person, driving offences, drug offences, offences against good order, offences against justice procedures and property damage. Carers in these families had received between one and 37 charges, with 16

carers being charged with offences in the six months preceding the infant's death. Two carers were on probation at the time of the infant's death.

**Domestic violence.** Domestic violence was present in 31 families (62.0%). Perpetrators of domestic violence were identified in 23 families (46.0%) and victims in 30 families (60.0%).

**Substance use.** Carers in 21 families (42.0%) had consumed alcohol and/or other substances in the period immediately preceding the infant's death. Carers were using methadone in 14 families and smoking marijuana in two families, and in one family the carer's drug use was not specified. Methadone was also detected in infants at autopsy in four of these families.

A history suggesting use of alcohol was evident in 16 families (32.0%) and use of other substances in 27 families (54.0%). Substances used included methadone, heroin, cocaine, amphetamines, benzodiazepines and marijuana.

**Mental health.** The carers in 19 families (38.0%) had been diagnosed with mental health problems prior to the infant's death. Diagnoses included Depression, Postnatal Depression, Bipolar Disorder, Schizophrenia, eating disorders, Attention Deficit Hyperactivity Disorder and anxiety disorders.

A logistic regression model was created to examine factors which may differentiate these 50 deaths from those where there was clearly no assault or neglect. The variables available for this analysis were restricted due to the severe limitations of the information available and the rarity of some events.

The variables examined were infant age at death, vulnerability of the infant, domestic violence, diagnosed mental health conditions of carers, and adult offending by carers.

The analysis revealed two factors as significant in differentiating between the groups. These factors were:

- vulnerable infants;
- diagnosed mental health conditions of carers.

Deaths where infants were identified as vulnerable were almost 11 times more likely to be assigned to the 'no clear determination possible' group ( $\text{Exp}(B) = 10.988$ ;  $p < 0.001$ ) when all other variables were held constant. This result is not unexpected, given that deaths that occurred in the context of a documented history of abuse or neglect (but where the cause of death was not clearly abuse or neglect) were assigned to the 'no clear determination possible' group.

Infants from families where carers had a history of diagnosed mental health condition were almost three times more likely to be assigned to the 'no clear determination possible' group ( $\text{Exp}(B) = 2.829$ ;  $p = 0.031$ ) when all other variables were held constant.

## 7.6 Conclusion

This component of the study reviewed the deaths of 186 infants over the three-year period 2000 to 2002 who died suddenly and unexpectedly after they were placed for sleep.

The extent and quality of information on the deaths examined in this study severely limited the Team's ability to accurately identify all deaths due to assault or neglect and those that occurred

in circumstances suspicious of assault and neglect. Within this limitation, the deaths of three (1.6%) infants were identified as due to assault and nine (4.9%) from neglect. For a further 50 infants, it was not possible to determine with any confidence whether the deaths were due to assault and neglect or not. It is therefore difficult to draw comparisons between the proportions of deaths due to assault found in this study with results from other studies.

This study found that two factors—infant vulnerability and care by a person with a diagnosed mental health condition—were significant in differentiating between the group of infants where there was clearly no assault or neglect and the group where it was not possible to determine with any confidence whether or not the deaths occurred in circumstances suspicious of assault or neglect.

While classification of assault, neglect or suspicious deaths always involves some subjective judgement, the failure to identify the cause of these deaths may leave other or future children in the family at significant risk. Alternatively the misclassification of a death as assault may result in wrongful accusation.

The information available on these deaths needs to be improved. Responding agencies are in the best position to obtain information on the death, and agencies with previous involvement with the infant or infant's family are an important source of historical information. Bacon and Tripp (2000) have argued that the best way to improve the information required to make an assessment of whether the death resulted from maltreatment is through a thorough investigation of the death and consultation and discussion with all professionals involved with the case.

The lack of information available on assault and neglect deaths limited the Team's ability to identify areas for prevention. Notwithstanding, the following deficiencies were identified: failure to recognise and report serious and unstable situations; inadequate risk assessment, including overestimation of a parent's ability and capacity to change; inadequate case planning, including provision of a suitable sleep environment for infants; and poor interagency collaboration and coordination.

All these issues have been identified by the Team in previous reports and recommendations made to address them.

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## Chapter 8 | Summary of findings and implications

The study aimed to: consolidate existing knowledge of unsafe sleeping environments; determine current parental practices in New South Wales in relation to modifiable risk factors that contribute to SUDI; describe current policy and practice in New South Wales when responding to these sudden deaths; and identify SUDI due to assault and neglect.

The study sought to identify:

- the gaps that exist in the information routinely collected in New South Wales for diagnostic purposes in relation to incidents of SUDI and the factors that influence the availability of the information;
- the strengths and limitations of SUDI policies and guidelines in New South Wales;
- the practices of New South Wales workers in responding to SUDI;
- the practices of parents in New South Wales in relation to modifiable risk factors, looking at parents of infants generally and parents of infants who died;
- what is known about SUDI cases where the infants have died as a result of abuse or neglect or in suspicious circumstances.

The rate of deaths determined as SIDS has fallen from 1.89 deaths per 1,000 live births in 1981 to 0.55 deaths per 1,000 live births in 2002. This change was largely due to the efforts of a number of services working in partnership including NSW Health, other health professionals, the SIDS associations and researchers.

However SUDI remains the second largest group (following transport fatalities) of potentially preventable deaths of children under 18 years of age. During the period 2000 to 2002 the Team identified an average of 62 SUDI cases. These deaths impact considerably on the parents of the infant and their families and the professionals involved in responding to the death. They represent a significant cost to the community not only in terms of a life cut short but also in resourcing the response.

The Team believes that more can be done to prevent these infant deaths and considers that action is required by the NSW Government to effect the necessary change.

This final chapter discusses the findings with respect to each of the study aims and recommends avenues for prevention. The recommendations are presented within a context of either prevention of or response to SUDI.

### 8.1 Summary of findings

#### Audit of the key information collected

An audit of the key information collected to establish cause of death where an infant dies suddenly and unexpectedly was undertaken of documents used routinely in New South Wales. Three documents were included in the analysis: the *Police Report of Death to Coroner* (P79A);

the *Death Scene Investigation Checklist – Sudden Infant Death (P534)*; and the *Final Autopsy Report*.

The analysis revealed substantial variation in data availability across the domains examined. In particular, there appeared to be gaps in the current routine data collection in relation to:

- psycho-social information about infants and their families (including contact with social service agencies and criminal history of parents and carers);
- clinical history of the family and infant;
- demographic information on the father or other carers and siblings;
- information on co-sleeping (co-sleeping is distinguished from bed-sharing, where a carer and infant share a bed for the purpose of feeding and settling); and
- the environment of the room in which the infant was found.

The study found data availability to be related to the way in which the data was collected. Data on a specific item was more likely to be available if it could be sourced from a standard question or format, rather than opportunistically revealed in an open text section of a document.

The study indicated that the current New South Wales data collection could be improved by standardising documents and using questions specifically related to incidents of SUDI that have been identified in the literature and Australian and international SUDI practice standards, guidelines and protocols.

### **New South Wales SUDI policies and guidelines**

An examination of the policies and guidelines in use in the agencies that respond to SUDI was undertaken.

The analysis revealed that the response to SUDI in New South Wales is provided by a number of agencies: the NSW Police, NSW Ambulance Service, NSW Health, the Department of Ageing, Disability and Home Care, the Department of Community Services, the NSW Coroner and SIDS and Kids NSW.

The study found that while the roles and responsibilities of the various agencies were clearly delineated, there were limitations in the response when compared with the key aspects of response identified in the literature including:

- Policies and guidelines relating to the support and guidance for parents were less prescriptive than those relating to investigative processes.
- The guidelines and forms available to those responsible for collecting and recording information do not support comprehensive collection.
- The level of expertise required to undertake tasks was not evident in many of the policies and procedures.
- Multi-agency case reviews occurred opportunistically, limiting the knowledge and skill available for each case and opportunities for continuous improvement.
- The monitoring and research activities are uncoordinated limiting prevention opportunities.

The study concluded that updating the policies and guidelines to address the limitations identified would improve the response to SUDI in New South Wales.

### Practices of New South Wales workers

The study into the operation of the response to SUDI in New South Wales obtained the views of police officers, ambulance officers, hospital workers, forensic pathologists, coroners, Department of Community Services workers, a SIDS and Kids NSW staff member and researchers. Interviews were conducted in urban, rural and remote locations.

Analysis was undertaken across four stages of the response to SUDI: initial response; post-mortem examination; attribution of cause of death; and research, monitoring and continuous improvement.

A range of issues were identified in the initial response stage including: participants feeling that they worked outside their areas of expertise; conflict between the various roles performed; inadequate knowledge and expertise in some areas; gaining knowledge and expertise through experience on the job; and cultural and practical impediments to receiving post-response support.

Issues identified in the post-mortem process, included variation in the quality and comprehensiveness of information received prior to the post-mortem examination; constraints on post-mortem testing; differences between pathologists' beliefs and practices regarding when and why to use SIDS as a diagnosis; and lack of appropriate feedback provided to parents and professionals involved in an infant death.

Other concerns were identified when attributing cause of death including the particular difficulties in attributing cause of death in infants and achieving a balance between the requirements of the investigation and the needs of grieving parents.

Finally, the analysis of the operation of the research, monitoring and continuous improvement stage identified the following impediments: poor information collection; severely limited opportunities for continuous improvement; and restrictions in obtaining human tissue samples for medical research.

Although there was variation in the extent and intensity of issues experienced across participants, three main areas of inadequacy were identified.

Firstly, responding workers did not always have the knowledge and experience required to undertake stressful roles. Secondly, the information required to undertake the essential tasks of autopsy, attribution, monitoring and research varied in quality and comprehensiveness. Thirdly, continuous improvement in New South Wales was restricted by limitations in the information available and the lack of systems to convey this information to those who required it.

Some of the issues identified were magnified in non-urban locations. The infrequent incidence of SUDI and their spread across the State presents a particular challenge for New South Wales.

The study concluded that the New South Wales policies and guidelines relevant to the response to SUDI were not consistently followed and varied across location and individual workers. Some workers were placed in situations which they were ill-equipped to handle, leaving them exposed and parents poorly supported. Accurate determination of cause of death and prevention efforts are thwarted and the capacity for learning and continuous improvement diminished.

### Modifiable risk factors and parental practices

A review of the national and international literature revealed strong research evidence for several risk factors relating to parental behaviour and the infant's sleep environment. The strongest and most consistent evidence for an association with SUDI has been found for:

- **sleeping position.** The back-down position is the safest sleeping position for infants. The face-down position has been repeatedly found to be strongly associated with SIDS. Side-sleeping has also been identified as a risk factor, partly because the position is unstable and infants are more likely to roll to the face-down position.
- **exposure to tobacco smoke.** Both maternal smoking during pregnancy and infant exposure to tobacco smoke after birth are significant risk factors for SIDS.
- **bed coverings.** Loose bedding that can cover an infant's head is associated with a high risk of SIDS. The risk is particularly associated with the use of bedding such as doonas or quilts which infants can slip under during sleep.
- **co-sleeping and smoking.** Co-sleeping can increase the risk of SIDS if the mother smokes or the caregiver shares a sofa or other inappropriate sleep environment with the infant.

To determine current parental practice in cases of SUDI the *NSW Child Death Register* was analysed to identify known risk factors. The results of the analysis indicate that in almost 90 per cent (86.6%) of SUDI cases modifiable risk factors were present including unsafe sleeping positions (40.9%), exposure to tobacco smoke during pregnancy and/or after birth (57.5%), head coverings (59.7%) and co-sleeping in combination with smoking and/or substance use (25.8%).

To determine current parental practices in the New South Wales population, information available through the *NSW Child Health Survey* was analysed. The analysis revealed that the majority of infants (62.3%) were put on their back for sleep from birth. However, 37.7 per cent were put for sleep in unsafe sleeping positions: 32.0 per cent were put on their side, 3.2 per cent were put face-down and 2.5 per cent were put in other or multiple positions. In 31.2 per cent of households at least one person smoked. Among mothers who responded to the survey, 12.8 per cent reported smoking in pregnancy.

The most consistent relationship found was with the mother's level of education. The likelihood of beneficial behaviours (putting a child for sleep on his/her back, no household smoking and no smoking in pregnancy) increased with increasing level of mother's education. The association was strongest with the highest level of education (tertiary degree or higher).

The study concluded that information campaigns may not be reaching some groups and should be modified to target specific subgroups. In addition benefits would be achieved by refocusing prevention efforts to stop the practice of putting infants for sleep on their sides.

### Infant deaths and fatal assault and neglect

The deaths of 186 infants over the three-year period 2000 to 2002 who died suddenly and unexpectedly after they were placed for sleep were reviewed to identify those that were due to, or suspicious of, assault or neglect. The extent and quality of information on the deaths severely limited the Team's ability to accurately identify these deaths.

Within this limitation the deaths of three (1.6%) infants were identified as due to assault and nine (4.9%) to neglect. For a further 50 infants, it was not possible to determine with any confidence whether the deaths were due to assault and neglect or not.

The study found that the categories of vulnerable infants and infants in the care of a person with a diagnosed mental health condition were significant in differentiating between the group where it was not possible to determine with any confidence whether the deaths were due to assault or neglect or not and the group where there was definitely no assault or neglect.

Deficiencies in agency practice were identified in the deaths of infants that occurred as a result of assault or neglect. Issues identified included: failure to recognise and report serious and unstable situations; inadequate risk assessment including overestimating a parent's ability and their capacity to change; inadequate case planning, including providing for a suitable sleep environment for infants; and poor interagency collaboration and coordination. All deficiencies have been identified by the Team in previous reports and recommendations made to address them.

The study concluded that better information gathering and sharing of the information gathered could assist in the investigation of incidents of SUDI and reduce the number of these deaths where the cause of death is undetermined.

## 8.2 Prevention of sudden unexpected infant deaths

Sudden unexpected deaths of infants are amenable to prevention. It is clear from the analysis undertaken of parental practices in New South Wales in relation to modifiable risk factors that a substantial number of infants under one year of age continue to be exposed to risk factors for SIDS and SUDI.

Considerable research has been undertaken to examine why parents refrain from or engage in risky practices, in particular their choice of infant sleeping position. This research demonstrates that the knowledge that parents had of risk factors for SIDS or SUDI, information provided by health professionals, information in printed material distributed by hospitals (such as magazines, newspapers and pamphlets), the attitudes and behaviours of nurses and midwives and whether alternative infant settling techniques were provided all contributed to the decisions parents made. Not surprisingly, if mothers knew that a particular behaviour was a risk factor they were more likely to refrain from that behaviour.

The findings of the analysis of parental practices in New South Wales suggest that information campaigns highlighting risk factors for SIDS and SUDI may not be reaching some groups as effectively as others. In relation to infant sleeping position it would be appropriate to select prevention interventions that target and work with parents with lower levels of education and families with more than one child.

To address household smoking prevention the findings suggest it would be appropriate to target families who are socio-economically disadvantaged, families with lower levels of parental education, where the father is unemployed and families living in socio-economically disadvantaged areas. Mothers who are Aboriginal or Torres Strait Islander and families living in rural and remote areas should also be targeted.

Preventions aimed at reducing smoking in pregnancy should target younger mothers, Aboriginal or Torres Strait Islander mothers, parents with lower levels of education and families where the father is unemployed.

**Recommendation 1:** The NSW Government and SIDS and Kids NSW should use prevention strategies that are effective with the high-risk groups identified in this study.

It is noteworthy that this study found that the majority of infants not put on their backs for sleep were put on their sides.

**Recommendation 2:** The NSW Government and SIDS and Kids NSW should place more emphasis on the risk associated with the side-sleeping position in prevention strategies.

Post-implementation evaluation should be undertaken for these two recommendations to assess their success.

**Recommendation 3:** NSW Health should monitor safe sleeping practices, including the use of the side-sleeping position, used by health professionals in maternity and neonatal wards.

There was ample evidence that because people learn through observation, modelling by health care professionals can have a powerful influence on parental behaviours. To provide parents with safe and appropriate infant care advice, health care professionals need to have the knowledge, attitudes and practice consistent with the known risk factors for SIDS and the *Reducing the Risk of SIDS* messages. This requires that health professionals have access to the best available evidence and a commitment to best practice and that agencies impart this information in the most effective way.

**Recommendation 4:** Professional bodies and NSW Health should disseminate information regarding modifiable risk factors for SUDI. This should be preceded by a study which investigates the most effective methods to disseminate this information.

In New South Wales SIDS and SUDI are monitored by the NSW Health SIDS Advisory Committee. All infant deaths are monitored and reported by the NSW Child Death Review Team. The National Coroners Information System makes available information on child deaths to researchers.

Information is required by these groups on SUDI and on unsafe parental practices. This information assists research efforts, enabling patterns and trends to be identified and targeted. The *NSW Child Health Survey* undertaken by NSW Health in 2001 included information on three of the known risk factors for SIDS and SUDI. The survey has been incorporated into the ongoing NSW Health Survey Program which is conducted year-round in New South Wales. It is important that this survey collects information on all risk factors for SUDI.

**Recommendation 5:** The New South Wales Health Survey Program should continue to collect information on SUDI and SIDS risk factors and on relevant social and demographic characteristics of parents.

### 8.3 The response following a sudden unexpected infant death

In responding to SUDI, several parallel functions must be served. Many studies have found the response to SUDI to be inadequate and in need of review (Centers for Disease Control and Prevention, 1996; Fleming et al., 2000).

A multi-agency integrated approach that describes the service system as a whole has gained considerable support. This approach acknowledges the diversity of specialist skills required, enables all aims of the response to SUDI to be met and guards against key aspects of the response being duplicated or omitted.

Five aspects of response have been consistently identified in the literature as important:

1. balance between care and investigation;
2. collection and recording of comprehensive information;
3. involvement of appropriate personnel;
4. multi-agency case review and continual improvement; and
5. monitoring and research.

Results from this study indicate that the response to SUDI in New South Wales fails to fully achieve these important aspects. The findings of the study and what is known from the international literature provide information to improve the development of the existing response.

One of the most obvious shortcomings relates to the collection and recording of comprehensive information to allow the various professionals to take appropriate actions and make informed decisions, including how parents will be supported. To achieve this, the information collected needs to be consistent with internationally recognised protocols such as the *Sudden Unexplained Infant Death Investigation Report*, the *International Standardised Autopsy Protocol* and the recent *Sudden Unexpected Death in Infancy – a Multi-Agency Protocol for Care and Investigation*. The Team believes that changing the information requirements would resolve this shortcoming. The Team notes that the NSW SIDS Advisory Committee intends to review the *Death Scene Investigation Checklist – Sudden Infant Death (P534)* used to collect information from the death scene and there are national moves to standardise autopsy practice relating to infant deaths. It is important that these initiatives occur as part of the examination of the statewide response to SUDI, within a multi-agency context and conform to international standards.

**Recommendation 6:** The NSW Government should align the information currently collected through the response to SUDI with internationally recognised protocols. It should emphasise multi-agency work, close collaboration and sharing of information and be gathered by professionals with appropriate training and expertise.

The Team believes that this can be achieved by the end of 2006.

Another shortcoming of the current response is the assignment of various aspects of the response to SUDI to professional groups which do not necessarily have the skill and experience to undertake them. The literature is clear that senior health professionals, including paediatricians, general practitioners or specially trained health visitors with knowledge of disease in childhood and bereavement, are best placed to obtain information from parents in the first instance. The *Confidential Enquiry for Stillbirths and Deaths in Infancy (CESDI)* argues that as the majority of SUDI do not result from unlawful actions it is inappropriate that the initial collection of information be normally or only carried out by a police officer as is the case in New South Wales. The examination undertaken in this study of SUDI resulting from assault or neglect supports this position.

Where information is obtained by professionals with expertise in the particular area of interest the information collection is enhanced. This is confirmed by the audit of key information undertaken as part of this study. Information obtained from the initial response had the highest availability for the death scene investigation domain and the lowest for the family demographic and psycho-social domains. This is not surprising given that this information is collected by police officers.

Where professionals undertake tasks within their area of expertise, the investigative, medical and psycho-social aspects of the infant's death are addressed and parents are supported. Further, the stress experienced by professionals without the necessary skill and experience in providing services outside their expertise is reduced. The findings from the interviews undertaken with police and ambulance officers establish this as an issue in the New South Wales response. This approach enables the balance between care and investigation to be achieved. Achieving this balance has been identified as one of the key aspects to a successful response to SUDI.

In considering how professionals with the necessary expertise provide the response in New South Wales, the infrequent incidence of SUDI cases and the geography and population distribution of the State need to be taken into account. With the exception of the autopsy examination, the New South Wales response is currently provided locally, with no particular agency personnel designated to provide the response. The result is that any worker within an organisation may be called upon to respond. While policies aim to provide the most senior staff to these deaths, the worker interviews undertaken in this study indicate that this is not always possible in practice, with inexperienced staff sometimes being called upon to attend cases beyond their abilities. Given that any individual will respond to a SUDI infrequently and the possibility of random assignment of staff, a comprehensive response cannot be guaranteed. The worker interviews suggest that this may result in inadequate information collection, death scene investigation, attribution of death and care and support for families.

**Recommendation 7:** The NSW Government should make sure that the tasks required are only undertaken by professionals with the appropriate role, knowledge (including up-to-date knowledge of relevant legislation, policies and guidelines) and expertise.

Advances in medical and forensic sciences have increased the ability of pathologists to identify metabolic and other medical causes of sudden unexpected death in infancy. Successful identification is based on wide and up-to-date knowledge and considerable experience in identifying the specific patterns of presentation of different conditions (The Royal College of Pathologists and The Royal College of Paediatrics and Child Health, 2004). The infrequent incidence of SUDI in New South Wales means that such knowledge and expertise is difficult to develop through generalist practice. Referral to a pathologist with specialist knowledge or experience should therefore be routine practice.

Further, pathologists do not always have the information considered necessary for the autopsy examination. Pathologists interviewed for this study indicated that they did not always undertake the tests they require to complete their autopsy examination because of the costs associated with obtaining the tests and the willingness of laboratories to undertake them. A further issue raised in the literature is the need to provide a result expediently. Others have suggested that it would be better to provide a preliminary diagnosis and follow this by a final one when all information and testing is complete. The possibility for this exists in New South Wales.

**Recommendation 8:** Pathologists should follow an agreed protocol and make consistent decisions. Post-mortem examinations should only be conducted by pathologists with specialist knowledge or experience, for example paediatric pathologists or forensic pathologists with specific training and expertise in paediatrics.

The Team believes that this can be achieved by mid 2006. This work will assist in allocating the various professionals' responsibilities in the response to SUDI.

Finally, the aspect of multi-agency case review needs to be addressed. Pathologists and coroners need to be supported in their tasks. Before commencing an autopsy pathologists require full briefing on the history and circumstances of the infant's death by the person who interviewed the parents and collected the initial information (Berry et al., 2000). Further, the pathologists interviewed in this study identified the absence of a full briefing as an issue in successfully undertaking their work. The policies and guidelines of the various agencies do not require such a briefing to occur.

The knowledge of a case is enhanced when all the available information is brought together. While the true facts of a case may never be determined, there is a greater possibility of this when all concerned with a particular case are able to contribute their piece of the puzzle. This is one of the main reasons for the CESDI recommendation that a multi-disciplinary case discussion be held locally after every sudden unexpected death in infancy. This practice is not required by any of the policies reviewed. Health professionals interviewed in this study indicated a clear desire to actively contribute to discussion of cases they were involved in and to provide the future care for the family identified through this process.

There is no central coordinator or coordinating body responsible for a uniform system response covering ambulance, police, hospital, forensic medicine and coroner's services and community services such as Department of Community Services, NSW Health (Community Health program) and non-government organisations such as SIDS and Kids NSW. The Team considers that the agency responsible for coordination of the response to SUDI and for the collection and sharing of the SUDI case information between all the relevant agencies needs to be identified.

The findings of both the policies and guidelines analysis and the worker interviews indicate that the New South Wales system is directed towards providing information to coroners to enable the manner and cause of death to be determined. Despite the belief by several workers that the coroner is responsible for coordination of the response, this is not the case. This confusion about the coordination role contributed to a number of issues identified by workers. These included the lack of ready access to information required to undertake their tasks and difficulties in contacting professionals in other agencies. Incidents of SUDI are largely preventable and the most relevant to general health prevention strategies. The Team considers that coordination by NSW Health is appropriate.

**Recommendation 9:** The NSW Government should adopt a multi-agency integrated system of response to sudden and unexpected deaths in infancy. This will involve agreeing on a definition, clearly identifying the tasks of individual agencies and professionals and developing a model of response. It should reflect the findings from this study and address the key aspects identified, including how to achieve the balance between care and investigation; collection and recording of comprehensive information; involvement of appropriate personnel; multi-agency case review and continual improvement; and monitoring and research. In developing the

response the needs of the family should be an essential consideration. NSW Health should lead the coordination of this.

The Team believes that this system should be developed by the end of 2006.

## 8.4 Conclusion

This research study consolidated existing knowledge of unsafe sleeping environments; determined current parental practices in New South Wales in relation to modifiable risk factors that contribute to SUDI; described current policy and practice in New South Wales when responding to these sudden deaths and identified SUDI cases where infants died as a result of assault and neglect.

The findings inform efforts to improve the scope and quality of information available in New South Wales in relation to infant deaths that occur suddenly and unexpectedly and in so doing maximise prevention efforts.

The analysis of parental practices and SUDI risk factors undertaken in the study indicated that information campaigns may not be reaching some groups and could be modified to target specific subpopulations. In addition benefits would be achieved by refocusing prevention efforts to address the practice of putting infants for sleep on their sides.

To assist in research efforts and identification of patterns and trends, information on parental practices needs to be collected continuously. The NSW Health Survey Program provides the means to achieve this.

International literature and professionals in the field have defined the key aspects of response to SUDI. In New South Wales these aspects are, at best, only partially addressed.

An integrated response is required, with the roles of all participants clearly stated and well delineated. The various aims of the response need to be identified and each adequately addressed. Focusing on some aspects of response to the exclusion of others leads to a disjointed system that does not achieve the main purposes outlined above. As stated earlier this can have far-reaching consequences, including rare inherited metabolic diseases not being identified, unsafe sleeping environments not being recognised, homicides not being detected leaving other children or future children in the family at significant risk and parents being wrongfully convicted of murdering their infants.

In developing the New South Wales response, consideration must be given to:

- which agency will coordinate the response;
- whether the response will be provided using a central, regional or local model;
- how a balance between care and investigation will be achieved;
- what information will be collected and recorded;
- how appropriate personnel will be involved in the various aspects of the response;
- the capacity for multi-disciplinary case review; and
- the various aspects of monitoring, evaluation, continuous improvement and research.

An updated, relevant and instructional model in New South Wales would have benefits for bereaved parents, for professionals, policy makers, researchers and for current and future infants.