Submission to the Committee on Community Services Inquiry into support for new parents and babies in New South Wales

November 2017

1. Background: the NSW Child Death Review Team

Since 1996, the NSW Child Death Review Team (CDRT) has been responsible for registering, reviewing and reporting to the NSW Parliament on all deaths of children aged from birth to 17 years in NSW.

The work of the CDRT is governed by Part 5A of the *Community Services (Complaints, Reviews and Monitoring) Act 1993* (CS CRAMA).

CDRT membership is prescribed by the Act. Members are:

- the NSW Ombudsman, who is the Convenor of the Team
- the Advocate for children and young people
- the Community and Disability Services Commissioner
- two persons who are Aboriginal
- representatives from NSW government agencies, including NSW Health, NSW Police Force, Department of Family and Community Services, Department of Education, and Department of Attorney General and Justice
- experts in health care, research methodology, child development or child protection, or persons who are likely to make a valuable contribution to the Team.

The Ombudsman, the Advocate and the Commissioner are statutory appointments.

Separately, and under Part 6 of CS CRAMA, the NSW Ombudsman is responsible for reviewing the deaths of children in circumstances of abuse or neglect, or in suspicious circumstances, and children who die in care or detention ('reviewable deaths').

The purpose of both functions is to prevent or reduce the deaths of children in NSW. To this end, we:

- maintain a register of child deaths in NSW
- classify deaths in the register according to cause, demographic criteria and other relevant factors, and identify trends and patterns relating to those deaths
- undertake research – either alone or with others – that aims to help prevent or reduce the likelihood of child deaths, and to identify areas requiring further research, and
- make recommendations as to legislation, policies, practices and services that can be implemented by government and non-government agencies and the community to prevent or reduce the likelihood of child deaths.

Our reviews

The main purpose of our review work is to identify opportunities for preventing the deaths

of children and young people. This is at two levels:

- at an individual level - the circumstances of death may highlight a particular risk.
- at a population level – we may be able to identify trends that point to the need for action to prevent deaths in certain demographic groups or from certain causes.

The NSW Registry of Births, Deaths and Marriages provides us with initial information about the deaths of children. Under CS CRAMA, certain agencies and individuals are required to provide information that we reasonably require to fulfil our functions. We seek and receive records from a wide range of sources, including health providers, forensic services, the State Coroner, the Department of Family and Community Services and other government and non-government agencies as relevant.

Information gained from reviews is placed on the child death register. The register informs our reports of child deaths to the NSW Parliament, and research initiatives that focus on the prevention of deaths of children in NSW.

Our reports

Both the CDRT and the Ombudsman are required to prepare a biennial report to the NSW Parliament about our work. Our functions also include research focused on prevention of child deaths. Below are links to reports relevant to your inquiry:

- Child Deaths from Vaccine Preventable Infectious Diseases, NSW 2005-2014 (August 2016) https://www.ombo.nsw.gov.au/__data/assets/pdf_file/0019/39412/NCIRS-child-deaths-from-infectious-diseases-report-2016-NSW-Ombudsman-final-1.pdf
- Child death review report 2015 (November 2016) https://www.ombo.nsw.gov.au/__data/assets/pdf_file/0009/39474/CDRT_review_report_2015_final.pdf
- Report of Reviewable Deaths in 2014 and 2015, Volume 1: Child Deaths (June 2017) https://www.ombo.nsw.gov.au/__data/assets/pdf_file/0004/45805/Report-of-reviewable-deaths-2014-and-2105_Child-deaths_Vol1_June17.pdf
- Childhood injury prevention: Strategic directions for coordination in New South Wales (November 2017) https://www.ombo.nsw.gov.au/__data/assets/pdf_file/0009/50130/Childhood-injury-prevention-Strategic-directions-for-coordination-in-New-South-Wales.pdf

This submission

The following information provides:

- An overview of deaths of infants, drawn from the NSW Child Death Register
- Issues for consideration by the Inquiry, based on our recent work relating to vaccine preventable infectious disease, Sudden Unexpected Death in Infancy, and abuse and neglect-related deaths of infants.

2. Overview: deaths of infants under one year

Over the past 10 years, the NSW child death register has recorded the deaths of 5501 children aged from birth to 17 years.[1] Over this period, there has been an ongoing decline in mortality rates for children across all age groups, primarily due to a significant decline in the rate of death of children from natural causes.

The majority of children who die in NSW are infants aged less than 12 months. Consistent with the overall decline in child mortality rates, infant mortality rates in NSW have also declined considerably.

Of the 5501 child deaths, infants less than 12 months of age accounted for more than half (3392, 61.7%) of these deaths.

Information from the NSW Child Death Register shows that:

- nearly three-quarters of the infants (2477, 73.02%) died in the neonatal period – within 28 days of their birth; of these, more than half (2044, 60.3%) died within the first week of life.

- just over half the infants (1925, 56.8%) were male; and 1467 (43.2%) were female. The mortality rate for male infants has been significantly higher than female infants over the past decade.

- while Aboriginal and Torres Strait Islander infants represent around five per cent of all infants,[4] they accounted for approximately ten per cent (10.2%) of infant deaths. The mortality rate for Aboriginal and Torres Strait Islander children in NSW, including infants, has consistently been significantly higher than comparable rates for non-Indigenous children.

- over half of the families of infants who died (53.3%) resided in areas of the greatest socio-economic disadvantage.[5]

- most infants die from natural causes – of the 3149 cases where a cause of death was identified, almost all (3063, 97.3%) the infants died as a result of natural causes. Conditions arising in the perinatal period (such as prematurity; respiratory and cardiovascular disorders; and maternal factors) and congenital and chromosomal conditions (for example, heart and neural tube defects and developmental disorders) accounted for most (2628, 85.8%) of these deaths; with the majority occurring in the first 28 days of life (neonatal period).

- eighty-six infants (2.7%) died from external causes, including abuse (12), drowning (10) – primarily in bathtubs, transport incidents (9) and other unintentional injury-related causes (55) – mainly accidental suffocation or strangulation in an unsafe sleeping environment (43 of the 55).

- a cause of death was not able to be identified for 210 infants (6.2%), even after thorough investigation including post-mortem examination.[6]

[1] Deaths that occurred between 1 January 2007 and 31 December 2016.
[4] Australian Bureau of Statistics (2013), *3101.0 Australian Demographic Statistics (TABLE 51. New South Wales, 2013)*, Canberra: ABS; Australian Bureau of Statistics (2012), *Indigenous experimental population projections by age, by sex – Reference period 2011*, Canberra: ABS.
[5] Calculated on data for the period 2011-2015.
[6] Final coronial information/cause of death information is not yet available for 33 infants.

3. Issues for consideration

Vaccine preventable infectious disease

Infectious diseases are caused by organisms such as bacteria, viruses, parasites or fungi and can be passed directly or indirectly from person to person. Examples include bacterial diseases such as pertussis (whooping cough), meningococcal infection and sepsis; and viral infections such as viral encephalitis, viral meningitis, and measles.

While child deaths due to vaccine preventable diseases are now rare in Australia, small numbers of deaths due to pneumococcal disease, meningococcal disease, pertussis, influenza and varicella have been reported in recent years. Over the last 15 years, 155 children in NSW died from infectious and parasitic diseases. The majority of children who died from this cause in the period were under five years of age, and male children consistently outnumbered females.

In 2014, the CDRT commissioned the National Centre for Immunisation Research and Surveillance (NCIRS) to analyse data held in the NSW Child Death Register regarding deaths from infectious diseases, over the 10-year period 2005-2014. A copy of the final report is appended to this submission.

The review found that despite the existence of a successful national immunisation program, deaths of children from potentially preventable infectious diseases continue to occur in NSW, particularly among infants. The review made a number of recommendations, including that:

- General practitioners and other immunisation providers should ensure that they are aware of the recommendations on influenza and meningococcal B vaccination in the Australian Immunisation Handbook, including that influenza vaccination is recommended for infants aged from six months, and meningococcal B vaccination is recommended for infants and young children.

- Immunisation of person's in contact with, and caring for, infants under 6 months at high risk of influenza, pertussis and varicella is recommended and should be promoted, particularly if vaccination has not been received in pregnancy; and also that comprehensive immunisation programs for workers in facilities that provide health care or child care services for high risk children and infants should be implemented.

- Pertussis and influenza vaccination during pregnancy should be promoted and encouraged by general practitioners, obstetricians and midwives to reduce the risk of disease in young infants.

It is worth noting that free seasonal influenza vaccine is currently only available for certain people, including Aboriginal and Torres Strait Islander children aged 6 months to 5 years, pregnant women, and people aged 6 months and over with medical conditions predisposing to severe influenza (such as cardiac disease, chronic respiratory conditions, and impaired immunity).

Influenza infection during pregnancy can lead to premature delivery and even death in newborns and very young babies. NSW Health reports that while influenza vaccination

represents the best protection pregnant women and their newborn babies have against influenza, vaccination rates remain low with only 1 in 3 pregnant women receiving the vaccine. Detailed further information in relation to influenza vaccination can be found at: http://www.health.nsw.gov.au/immunisation/pages/seasonal_flu_vaccination.aspx

Sudden Unexpected death in Infancy

In recent years the CDRT has undertaken considerable work in relation to this issue.

SUDI is a classification rather than a cause of death. The CDRT defines SUDI as the death of an infant aged less than 12 months that is sudden and unexpected, where the cause was not immediately apparent at the time of death. Excluded from this definition are infants who died unexpectedly as a result of injury – for example, transport fatalities – and deaths that occurred in the course of a known acute illness in a previously healthy infant.

The infant mortality rate for SUDI has, overall, declined since 2001. Notably, however, the rate has not changed significantly since 2008. In addition, the overall decline reflects a change in post-neonatal SUDI (infants older than 28 days).

Over the past 10 years, 497 of the 3392 infant deaths (14.7%) have been classified as SUDI. The majority of these infants had been placed for sleep, either on their own or with others. Other infants died after being placed for the purpose of feeding or settling, which in most cases resulted in unintentional bed sharing. A small number of infants were suddenly taken ill and were attended by emergency services.

Our reviews have found that many of the infants whose deaths are classified as SUDI were in unsafe (non-infant specific) sleep environments when they died, including infants who were sharing a sleep surface or who had been placed for sleep in an adult bed or on a couch. Other infants died in circumstances where risk factors such as prone sleeping and/or loose bedding were evident. The majority of infants were also found to have been exposed to tobacco smoke.

It is critical that clear messages about safe sleep and safe environments are developed and delivered effectively, and that resources are made available to support families to make choices that avoid exposing babies to external factors associated with increased risk of SUDI. Health professionals who have contact with babies, infants, expectant parents, or families with babies, have a significant role in the reduction of the incidence of SUDI by providing and promoting consistent information and modelling safer sleeping practices. The Team has made recommendations to NSW Health in relation to the promotion of safe sleeping practices, and are actively monitoring the progress of initiatives.

SUDI is disproportionately affecting infants in disadvantaged and vulnerable families

SUDI affects families from all socio-economic backgrounds; however increasingly, it is families residing in areas of low socio-economic advantage; families with a child protection history; and Aboriginal and Torres Strait Islander families that are over-represented in SUDI. Over the five years from 2011 to 2015, almost 50% of SUDI were from families living in areas of greatest socio-economic disadvantage.

The CDRT have identified there is a clear need to better target initiatives to work effectively with vulnerable families to promote safe sleeping and other preventative practices. Red Nose (formerly SIDS and Kids) has also identified the area of vulnerable populations in high income countries as a key area for priority to improve outcomes in child mortality and to prevent SUDI.

These findings highlight the important role of NSW Health and FACS to target safe sleeping and other risk-related messages specifically to disadvantaged families. The CDRT have recommended that FACS and NSW Health should jointly consider the applicability of relevant initiatives in other jurisdictions that target high risk populations. The CDRT has also recommended agencies review strategies targeted to young mothers, including use of alternative avenues of advice through social media and parenting blogs, and targeting grandmothers for safe sleep education.

Our work, and that of FACS, has also highlighted the need for child protection caseworkers to focus on SUDI risk factors in families caring for an infant, particularly when assessing risk in the context of parental drug use

The proportion of explained SUDI is unacceptably low

Deaths classified as SUDI are either:

- explained SUDI – deaths where a cause is found after investigation, or
- unexplained SUDI – deaths where the cause remains unidentified after all investigations are completed. This includes deaths that are classified as Sudden Infant Death Syndrome (SIDS).

Most (326, 65.6%) of the 497 deaths classified as SUDI are unexplained; with explained SUDI accounting for less than one-third (145, 29.2%) of sudden and unexpected infant deaths. In cases where a cause of death is subsequently identified, most (90, 62.1%) are found to be due to natural causes following post-mortem examination. Other explained SUDI are, in the main, due to external causes such as unintentional threats to breathing, as well as rarely, assault and drowning.

Identifying a cause of death for SUDI is important for a number of reasons:

- for parents and carers, to understand their loss
- to provide information about possible medical or genetic implications for the family
- to learn from untimely deaths and help prevent future deaths, and
- to identify any possible suspicious deaths.

In NSW, a cause of death is able to be determined (on average) in less than one-third of SUDI. This is much lower than best practice, which indicates the proportion of explained SUDI should be closer to half.[9]

Identification of a cause of death requires a timely, expert-led and comprehensive

[9] Garstang J, Ellis C, Sidebotham P (2015), An evidence-based guide to the investigation of sudden unexpected death in infancy, *Forensic Science, Medicine and Pathology* DOI.1007/s 12024-015-9680, Springer, New York.

investigation following the sudden and unexpected death of an infant.

SUDI investigation in NSW involves the NSW Police Force, NSW Health (including forensic services), and the State Coroner; however, there is currently no whole-of-government policy to direct the cross-agency coordination of responses to SUDI.

The CDRT has identified significant gaps in investigation of SUDI in NSW. In order to improve identification of cause of death, and therefore to potentially help to prevent SUDI in the future, the CDRT has recommended a clear whole-of-government directive should govern SUDI investigation in NSW. A revised model, drawing on contemporary recognised best practice, should incorporate strategies that are not part of the current approach, including:

- Expert paediatric assistance in death scene investigation and interviews with the family (noting that investigation of any suspicious deaths would be the responsibility of police).
- Specialised training and development of resources for police in SUDI investigation.
- The conduct of SUDI post mortems by specialist paediatric pathologists, or minimally, consultation with paediatric specialists.
- The introduction of multi disciplinary review following post mortem to consider all available information and provide advice to assist the Coroner in determining cause of death, to advise on possible genetic issues and necessary investigations for surviving children and parents, and prevention strategies for the family in the context of identified risks.

At the time of writing, we note there is broad support for a change in the approach to SUDI investigation across agencies with a role in responding to SUDI. The NSW Government has advised it is currently consulting with agencies on options to improve the whole-of-government response to SUDI. The CDRT welcomes this support and will continue to actively monitor and report on progress in this area.

Abuse and neglect

Child protection history

In 2014, the CDRT tabled a special report to Parliament on the causes of death of children with a child protection history between 2002 and 2011. The analysis for this report was undertaken by the Australian Institute of Health and Welfare.[10]

In relation to infants under one year of age, the research found that a child protection history significantly increased the odds that a baby would die:

- suddenly and unexpectedly (SUDI)

[10] NSW Child Death Review Team (2014) *Causes of death of children with a child protection history 2002-2011*, report by the Australian Institute of Health and Welfare. NSW Ombudsman, Sydney. The report can be accessed from our website - https://www.ombo.nsw.gov.au/news-and-publications/publications/reports/child-death-review-team/causes-of-death-of-children-with-a-child-protection-history-2002-2011-special-report-to-parliament

- from external (injury-related) causes, including unintentional causes such as accidental suffocation or strangulation in bed, and drowning; and from intentional causes (abuse)

- from respiratory illnesses, such as influenza and pneumonia.

In addition, the analysis found a higher proportion of deaths of babies with a child protection history remained unexplained, compared with babies without a child protection history.[12]

Children with a child protection history are, by definition, a vulnerable group. Identifying both natural and external causes of death where these children have a significantly higher risk of death is important for progressing work related to the prevention of future deaths. Of relevance to the current Inquiry, the findings highlight the potential importance of universal early intervention services in identifying families where additional supports may be required, and point to possible opportunities for future work in the targeting of prevention strategies. The research also supports the findings and recommendations of the Team in relation to SUDI, and underscores the importance of this work.

Abuse and neglect-related deaths of infants

The NSW Ombudsman's work in relation to 'reviewable' child deaths has established that very young children (0-4 years) are over-represented in abuse and neglect-related deaths.

Abuse and neglect-related deaths represent a small but significant proportion of child deaths in NSW – approximately four percent of all child deaths.

Over the past 10 years, 210 children died in circumstances of abuse or neglect. Just over one-quarter of these deaths (60, 28.6%) involved infants under the age of 12 months; 43 infants died in circumstances of neglect, and 17 due to abuse.[14] The majority (47) of these infants had a child protection history.

Neglect-related deaths

Cases are considered neglectful because the actions of a carer are identified as significantly careless or an intentional or reckless failure to adequately supervise, or result from the failure to provide for a child's basic needs, including food, shelter and medical care.

Most neglect-related infant deaths (36 of 43) are classified as SUDI. The seven infants whose deaths were not classified as SUDI died from drowning (5), in a transport incident (1) and from injuries sustained during an unassisted birth (1).

For the 36 infants where cause of death was not immediately apparent at the time of the fatal incident, a cause of death was subsequently identified for one-third (12) of the infants: four infants died from natural causes (mainly pneumonia-related); the remaining eight deaths were due to external causes, primarily accidental suffocation or strangulation in an unsafe sleep environment.

[12] NSW Child Death Review Team (2014), *Causes of death of children with a child protection history 2002-2011*, special report to Parliament, Sydney: NSW Ombudsman.
[14] Including deaths that occurred in circumstances that were 'suspicious' of abuse or neglect.

A context of unsafe sleeping was also a key factor in almost all the cases which remained unexplained after investigation (22 of the 24 cases); in most (16) instances infants were co-sleeping with a drug and/or alcohol affected parent(s), and an element of accidental asphyxia could not be excluded with certainty. In other cases infants were left to sleep overnight in bouncers, placed to sleep in broken cots or bassinettes filled with excessive bedding or other objects that posed a clear suffocation risk, or were left unattended for excessive periods of time in unsafe situations.

Regardless of whether a cause of death was identified, the cases raise strong themes of severe environmental neglect beyond the immediate circumstances of death, and a lack of attention to the needs of very young infants by their carers which is often associated with parental drug or alcohol use, but also with transience, overcrowding, and other family dysfunction.

Abuse-related deaths

Unlike neglect, only a small number of abuse-related infant deaths are classified as SUDI. This is because in most cases (12 of 17), the infant was presented to health professionals with obvious life-threatening non-accidental injuries, or the circumstances surrounding the fatal incident clearly indicated intentional harm. For those cases where no signs of intentional injury were immediately apparent, evidence of suspicious injury was found during autopsy, and/or concerns about abuse were identified by police during their investigation.[15]

Parents, or a person acting in a caring role, are almost always (16 of the 17 cases) found to be responsible in cases of infant homicide. In some (3) cases, both parents are implicated; however in most (9) instances the father or male defacto partner of the mother was identified as having caused the fatal injuries. A mother was responsible for the death of her infant in four cases, including one case where the mother was suffering from a severe undiagnosed mental illness.

Our reviews of abuse-related deaths have found, amongst other things, that young children are most vulnerable to fatal abuse; that the nature and extent of risk is not always recognised or understood; and that frontline services, particularly maternity and early childhood services, have a key role in identifying and responding to child protection issues in vulnerable families, particularly in response to physical injury and mental health.

Observations in relation to abuse and neglect

Maternal mental health

The issue of maternal mental health, and support to children of parents with mental illness, is one area where the NSW Ombudsman has undertaken considerable work.

In 2014-15, we investigated the actions of agencies in response to concerns about the safety and welfare of a toddler who died in circumstances of abuse. The child and family had complex needs, and as a result, the family was provided with a high level of support from a number of agencies. In this context, it was important that the actions of all involved agencies were coordinated and informed by the interventions, strategies,

[15] Includes two cases where final coronial information is not yet available.

identified issues and outcomes of work by other involved agencies. Our investigations found that this was not the case. We found that:

- Despite the family's significant contact with services, none of the involved agencies sought to bring all of the parties together to:
    - clarify the roles and responsibilities of each agency
    - discuss the child protection risks and how these would be monitored and escalated if required
    - discuss what and when information needed to be shared between the agencies, and
    - agree on a plan for coordinating the provision of services.

- There was inadequate communication between relevant services about the progress and outcome of respective service interventions – as a result, it appeared that agencies often made assumptions about the nature, effectiveness and protective impact of work by other agencies.

- Some practitioners tended to respond to changes in family circumstances by making new referrals, rather than reviewing the effectiveness of existing interventions or therapeutic strategies, and adjusting the intensity or focus as indicated. Although it was not always evident what improvements were being achieved by the involvement of multiple services, it appeared that for some practitioners, the number of services involved was in and of itself considered protective for the child.

The circumstances of the child's death resulted in internal reviews by involved agencies, and interagency discussions to identify barriers to good practice and strategies for change.

The issues identified in this case in relation to the need for a coordinated approach by agencies are relevant in many cases, and are closely linked with the concept of shared responsibility, a hallmark of the NSW child protection system since 2010. It refers to the principle that child protection is the collective responsibility of the whole-of-government and the community.

Our previous reports of reviewable child deaths have noted the ongoing and significant challenges for agencies in engaging and responding effectively to families with complex needs. We have also highlighted the importance of early assessment and intervention, and effective coordination and collaboration between agencies working with these families.

<u>Drug and alcohol misuse</u>

The risks to infants and children associated with carer substance abuse are well known, and where parenting capacity is affected, the impact on babies and young children can be significant. Carer substance abuse was a significant issue in reviews of abuse and neglect-related deaths.

In 2015, we reported on initiatives by FACS and NSW Health to improve responses to risks to children in the context of parental substance abuse, and strengthen guidance for workers. We note that NSW Health funds Drugs in Pregnancy Services across NSW, which are designed to improve the management of substance use in pregnancy and to

improve follow up services for families.

In 2017, we undertook a review of children who died in neglect-related circumstances over the ten-year period 2006-2015. The group included 49 infants under 12 months old (over one-third of all cases considered), reflecting the vulnerability of very young children and their strong reliance on carers to meet their basic needs and to keep them safe. Our review identified that alcohol and/or other drug abuse was the most significant single risk factor contributing to the neglect-related deaths of children, and the predominant risk in the background of the children who died.

Following on from the cohort review and our previous work in this area, we are currently undertaking a further research project focusing specifically on the role of alcohol and other drugs in reviewable child deaths. We plan to publish the results of this work in 2018 or 2019.

Domestic violence

In 2015, we conducted a review of familial abuse-related child deaths in NSW over a 10-year period, 2004-2013. One of the issues we identified was that new partners (male intimate partners who had formed a relatively new relationship with a birth mother) represented a significant proportion – almost one-third – of all persons of interest / offenders.

The identification and assessment of risk presented by new partners is an issue that FACS also recognises is important, and a *New Partners and New Household Members Practice Tool* is in place with accompanying practice advice to guide caseworkers.

Contact: Monica Wolf, Director Reviews, Inquiries and Complaints

(02) 9286 0982

mwolf@ombo.nsw.gov.au