Sudden Unexpected Death in Infancy Prevention in New Zealand:

The Case for Hauora – a wellbeing approach

**Acknowledgements**

Koha Aperahama, Alayne Hall, Christine McIntosh, Ed Mitchell, Heather Muriwai, Kate Nicoll, Kelly Spriggs, Tania Tetitaha

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# Purpose

This report reflects sentiment among the Expert Advisory Group on SUDI Prevention around consideration of the wider systemic issues impacting the SUDI deaths that occur largely among Maori, Pacific whānau. The EAG proffers this advice on the basis of a recent analysis of the Coronial SUDI Liaison Reports of 64 infants deaths spanning July 2019 – June 2020 undertaken for the Ministry of Health by Professor Barry Taylor and Ms Anna Foaese. The EAG have taken a viewpoint on the findings of Taylor & Foaese that leads to different, but mostly complementary, recommendations.

In doing so, we strongly advocate the need to commission a SUDI prevention approach that moves away from a didactic reliance on parent(s) changing SUDI-risk infant care practices towards the development of systems run by Māori and Pacific women that engage whānau and communities in the provision of optimal care and safety for infants with a Hauora- wellbeing approach, which gives expression to the multifaceted nature of the complex lived realities of many whānau who care for infants.

#

# The Landscape: SUDI in New Zealand

Sudden Unexpected Death in Infancy (SUDI), once known as Sudden Infant Death Syndrome (SIDS), is a leading cause of infant mortality for many countries in the developed world. With a relatively low overall rate of infant mortality internationally, New Zealand has one of the highest rates of SUDI, with huge inequities for Māori and Pasifika infants.

## Early days: Raising SIDS risk-related awareness

SIDS rates decreased markedly with the SIDS-risk related changes in infant care practice emphasized by the 1991 National SIDS Prevention campaign. Those risks included prone infant sleep position, maternal smoking, bedsharing and not being breastfed. The decrease in the national SIDS rate was rapid and marked. Beginning from much higher point, there was a similar trend among Māori which began 4-5 years later after the introduction of the Māori SIDS Prevention Programme. These deceasing mortality rates attenuated for all infants in the 2010s and, now labelled as SUDI, became even more disproportionately high among Māori, and increasingly over the years, Pasifika infants. Smoking during pregnancy, bedsharing with an infant and the combination of the two, all of which are more common in Māori and Pasifika families, have become the (SUDI-risk related) infant care practice(s) deemed responsible for this disparity.

## Developments: Supporting a change of (SUDI risk-related) infant care practice

In response to the mortality disparity, a 5 year plateau in rates, and the ongoing smoking-bedsharing SUDI risk amongst Māori, the wahakura - a flax bassinet that (in theory) enabled safer bedsharing - was promoted in 2006, and a similar plastic device (the Pēpi-Pod®) quickly followed in 2010. Both served as a focal point for safe sleep education, the latter with an expectation to share this knowledge. With the capacity for mass Pēpi-Pod® production developed by the Change for our Children programme following the 2011 earthquakes in Christchurch, the Safe Sleep Programme was developed with District Health Boards (DHB) and began to systematically distribute infant sleeping beds and safe sleep education among whānau at risk of SUDI (Tipene-Leach & Abel, 2019). There was a significant reduction in post-perinatal deaths across the years 2010 to 2015 that was attributed to the Safe Sleep programme and its associated educational aspect (Mitchell, Cowan, Tipene-Leach, 2016; Cowan, 2010). Concurrently, DHBs and well child providers such as Plunket and Māori and Pacific providers were identifying ways of incorporating SUDI prevention messages into their workforce development and family engagement systems (Editorial, Best Practice Journal, 2013). In 2017, the Minister of Health announced a significant boost to SUDI prevention funding and an ‘adoption’ of the Safe Sleep Programme by the Ministry of Health.

Smoking cessation had always been recognised as the ‘other place to go’ with the prevention of SUDI, but cigarette smoking, widely recognised as a marker of deprivation, is difficult to change and limited progress has been made. Inappropriate information or limited appeal has been raised as factors to explain the lack of engagement with Māori women (Glover et al, 2012).

## The second mortality plateau

The second half of the 2010s decade saw another plateau of Māori deaths with an upwards trend since 2018. Pacific SUDI rates fluctuate over that time, a small numbers effect, but the disparity is persistent. In the July 2019 – June 2020 (the period of the Taylor & Foaese report) there was an upward trend of SUDI rates for all ethnicities. This has all occurred despite determined distribution of the infant sleeping beds (wahakura and Pēpi-Pod®) by DHBs, and the instigation of the national SUDI prevention programme adopted by the Ministry of Health in 2018 (Ministry of Health, 2020). This has prompted an internal review by the Ministry of Health, drawing on provisional data from the Coroner’s Office and data collected by SUDI liaison officers in that July 2019 – June 2020 period.

*‘SIDS/SUDI prevention in NZ has been about change of infant care practice. The Māori SIDS Prevention Programme added culturally resonant social outreach and the wahakura added a culturally resonant intervention’.*

# Internal review: new insights

The 2020 Taylor & Foaese report from the Ministry of Health explores data on 64 infant deaths collected between July 2019 and June 2020 by SUDI liaison officers, who routinely collect a vast array of data for the Coroner from families who have experienced the loss of an infant to SUDI. The review documents the ongoing significance of previous findings that relate to SUDI deaths such as the correlation with maternal smoking, bedsharing and infant sleep position, however, it also brings some new insights that add important context to the development of SUDI prevention in the years ahead.

## SUDI Knowledge

The analysis found that the whānau/carers knowledge of SUDI risk factors was relatively good, that is, that the safe sleep messages were heard by SUDI parents - although acting on this knowledge was more limited. For example, although the dangers of direct bedsharing were understood, on the night of the SUDI death many infants were bedsharing with an adult - and in some cases, there was an safer infant sleep bed in the household that was not being used. Whether this non-use was habitual or occurred only on that night is not known. Neither is the occurrence of direct bedsharing known amongst this demographic population group where a SUDI death did not occur.

Similarly, the risks of smoking in pregnancy were understood by mothers but many of them were unable to take advantage of smoking cessation opportunities. The reasons for this were not elicited by the survey.

## Carer Fatigue and/or Sick Child

The review identified that extreme maternal or paternal tiredness was a significant theme in SUDI cases alongside caring for an acutely unwell infant or an infant with *a “pre-existing condition such as Intrauterine Growth Restriction (IUGR), inadequate weight gain, prematurity, intrauterine toxic brain impairment, surgical hernia repair, or recent secondary care”.* Both factors were associated with subsequent decisions to bedshare with infants who were *“unwell”, “having difficulty breathing”, “unsettled”* or “*irritable”*. There is no contextual data around how common extreme parental tiredness or such infant unwellness is in the population group, but importantly, these factors and the choice to bedshare are likely to be intimately related.

## Financial Insecurity

This dataset has provided new data on financial insecurity. Previously, assumptions have been made about socio-economic status based on the Deprivation Index of the address, but whānau are now directly asked how they “made ends meet”. Less than 20% of whānau were living without considerable financial insecurity. For instance the review documents that families were “*in most cases residing in shared accommodation, boarding, renting and living in one room*”. Such housing circumstances are clearly linked to the ease with which families, can provide safe sleep conditions.

*‘Poverty and poor housing, the advent of sick kids and exhausted parents are
likely to be intimately related to the decision to bedshare on the
night of the SUDI death’.*

# What are the real drivers behind SUDI?

The significant SUDI risk-related infant care practices have been discussed as has the shaping of the national response to SUDI around those infant care practices. However, the plateau in mortality from 2012/13 onwards and increase over the past two years points to a need to for a SUDI prevention strategy that looks beyond simply trying to influence infant care practice.

## Poverty

The Taylor & Foaese review points towards the significance of poverty and other social determinants of health that impact on whānau and are in the circumstantial foreground of SUDI deaths. The review makes this clear saying *“Less than 20% of SUDI whānau in this dataset were living without considerable financial insecurity”* and above we saw that *“in most cases”* families were living *“in shared accommodation, boarding, renting and living in one room”.* Clearly, poverty and housing circumstances limit opportunities to provide safe/separate sleep arrangements and, we speculate, are also related to broader stresses that affect the own wellbeing of the carer, the ability to access and provide optimal care and make good health-related decisions. A significant improvement in financial security is likely to improve all the above factors.

## Engagement with whānau

We observe, as the review does, that in general parents of SUDI infants are aware of what the risk factors for SUDI are and that for one reason or another they have chosen to act in a fashion contrary to best advice. Although (as above) we think this is related to the desperate living circumstances that whānau exist in, we also posit that the services and service providers fail to engage appropriately with whānau, simply do not suit the whānau in a socio-cultural sense, or that the whānau are overly ill-equipped to recognise how they could take advantage of what is offered.

A systematic review of interventions to improve safe sleep practice, interventions to improve engagement with services, and parental decision-making around infant sleep environments by parents at high risk of SUDI (Garstang et al, 2021) found that interventions that showed some successes were all ‘*face-to-face programmes with high intensity family contact and close working and co-ordination between agencies and community support’.* The review went on to identify the importance of quality relationships between skilled professionals and families and that non-judgmental engagement is essential to achieve meaningful change. We believe, as does Pacific Perspectives (2013) working in South Auckland, that the lack of such engagement is significant in facilitating the failure of SUDI prevention to take hold among Māori and Pasifika families in dire living circumstances.

## Smoking in pregnancy

Smoking in pregnancy is widely known to be related to socio-economic status. Glover, Fraser & Nosa, (2012) show, as did the Taylor & Foaese review, that 70% of smoking pregnant woman did not take the opportunity to attempt a quit programme. Uptake of smoking cessation by Māori women living in poverty is clearly complicated and, when considering variations in quit rates between Māori and European New Zealanders, Barnett, Pearce & Moon, (2009) talk about shifting attention “*from policies that focus solely on engineering individual behavioural change, to an inclusion of the role of environmental stressors such as community inequality”.*

## Infants who are sick

Not surprisingly, the prevalence of infant illness is higher among families living in deprived circumstances with inadequate housing. Although this review indicated that families had often accessed care of some sort in the recent illness, the nature of those illnesses (either acute respiratory or chronic developmental) are not ones where a service-related treatment/cure was particularly useful – they had all been returned their inadequate homes and had subsequently died. The SUDI whānau was immersed in cumulative problems: a previously compromised infant; who is/has become sick; is living and sleeping in unsafe conditions; with a parent (the review tells us) who is exhausted and (we surmise) is ‘at their wits end’. These are the circumstances in which a poor decisions are made and infants die.

## Mental health

Taylor & Foaese say that mental health (requiring medication) were present in five of the 64 cases and excessive alcohol use present in 10 cases - with 3 of those cases being a likely cause of suffocation, but as with the factors above, we do not know how common these factors are in the wider population. Stress and maternal mental health issues are intimately linked to the struggle to make ends meet by whānau living in deprivation and recent report on maternal mental wellbeing during pregnancy and the first year of life one in five mothers reported mental distress during that time pregnancy and half of indicated that they were *‘deeply afraid of formal support services and spaces’* and would not seek help for fear of their baby being taken away from them (Health Promotion Agency Te Hiringa Hauora, 2020). The enquiry format of the SUDI Liaison officers has very likely underestimated the prevalence of mental health issues, and we all understand in the present context, that it will be particularly difficult for whānau in this population to access appropriate and acceptable mental health services.

## ‘New’ services that don’t talk to each other

The funding of the most recent national SUDI prevention programme occurred in late 2017. It was commissioned to coordinate SUDI prevention work and provide infant beds and Safe Sleep education across the country. Previously a single national contract run by a Kaupapa Māori service provider working for Auckland University, the new service was broken down into more than 20 contracts: the National SUDI Prevention Coordination Service (contracted to Māori provider, Hāpai Te Hauora), the Regional Coordinator Services (contracted to two different non-Māori providers and a number of DHBs) and the balance dispersed individually amongst 20 DHBs for purchase and distribution of safer infant beds. The provision of safer infant beds continues to be an important prevention approach; it creates a mechanism to carry the safe sleep message as well as providing a safer infant sleep environment. But whether safer infant beds make it into the homes of those who most need them, whether follow-up messaging around safe sleep occurs and whether the devices are actually used is not known where there has been no SUDI incident.

*‘The plateau in mortality from 2012 onwards and increase over the past two years points to a need to look beyond influencing infant care practice’.*

# A Hauora wellbeing approach that is led by Māori and Pacific women

## SUDI occurs primarily in Māori and Pacific communities

The review reminds us that sudden infant death occurs inequitably among Māori infants who nine times more likely (RR 8.96), and Pasifika infants who are six times more likely (RR 5.85) than non-Māori, non-Pacific infants and consequently, the SUDI Expert Advisory Group see the need for Maori and Pacific leadership with new approaches in the planning, delivery and evaluation of SUDI prevention programmes. Investment in Maori and Pacific SUDI prevention approaches and Māori and Pasifika health workers is vital.

Research with Maori and Pacific families have long identified the need for SUDI prevention strategies that operate at a more structural level (Tipene-Leach, 2010). Labelling structural change as “non-modifiable” has kept the emphasis on the individual and/or whānau changing their behaviour as the primary means to reduce SIDS risk and has circumvented exploring how to modifying these determinants. This goes hand in hand with a lack of political will or appropriately applied resource to prevent the sudden deaths of Māori and Pacific infants living in difficult circumstances. Addressing SUDI seems focussed on solutions that are easily mapped across to the baby’s sleeping environment, and much of what we have already been doing can continue to form part of a wider strategy - but we can no longer ignore the determinants that were previously termed ‘non-modifiable’. We must now consider these ‘essentially modifiable’. Anti-poverty strategies range from lifting welfare benefits through to proposals for a Universal Basic Income (Rankin, 2016). Regardless of policies from each government of the day, market forces such as the ever-soaring food prices and the housing market add further stresses for families

Poverty affects multiple outcomes for children at the same time (Ministry of Social Development, 2018) and if we see the impact of poverty from this broader lens, as SUDI prevention advocates we would collectively find ways of advocating for broader income and housing related policies. Challenging the social and economic determinants of health requires a cross-sectoral approach to acknowledge the limitations of Vote Health and the importance of income and prosperity, housing, education, justice, race relations, gender, and the intersectionality of all of these. Of all these factors, income has long been identified as the single most important determinant of health (National Advisory Committee on Health and Disability, 1998).

### Recommendation 1:

#### The EAG recognise the relief of poverty as a fundamental measure in the prevention of SUDI deaths.

**Alignment with the Māori Health Authority**

This year, a planned National Health Authority that will centralise the commissioning, policy and planning functions of the sector alongside a Māori Health Authority that responds better to New Zealand’s bicultural governance framework was announced (Health and Disability System Review, 2020). Aligning with this, the EAG recommends that SUDI investment moves towards a centralised, bicultural framework that recognises the significance and effectiveness of Maori leadership. This leadership should be responsible for coordinating all functions of SUDI prevention including safe sleep messages, supply of safer infant beds, credentialing of wānanga wahakura kaiako, national conference opportunities for infant care kaimahi, monitoring of outcomes and the development of post-SUDI whānau services – all using mātauranga Māori to enhance appropriate and engaging messages, workers and services.

### Recommendation 2:

#### The EAG strongly recommend alignment of SUDI commissioning with the new Maori Health Authority, providing support for Māori and Pacific leadership and the centralisation of prevention programme management.

**A fundamentally Maori and Pacific Framework**

In 2019, the Ministry of Health and Te Puni Kokiri commissioned research to explore what primary health care would look like if the principles and approaches of Whānau Ora were applied. Te Piringa (2020), a Maori and Pacific framework, found that the values and principles found in every successful case study acknowledged the importance of relational and holistic approaches and that whānau-led models provided for transformational and impactful change. We reiterate, the evidence of Garstang et al, (2021) who found that successful SUDI interventions were ‘*face-to-face programmes with high intensity family contact”* and relied on quality relationships and non-judgmental engagement.

EAG members and frontline staff who work most closely with Maori and Pacific whānau or who are themselves Maori and Pacific, cannot emphasise enough the importance of culturally anchored solutions that are developed in partnership with, or led entirely by, whānau/aiga. Maori and Pacific frontline workers and providers talk about the importance of ‘aroha/alofa’ and the importance of genuinely listening to what whānau are saying and the development of programmes that have meaning for them.

Such an approach is at the heart of a Hauora wellbeing approach where SUDI prevention is not the sole goal, rather it is the prevention of a wide array of illnesses and poor outcomes that will make a lasting difference for children and families.

### Recommendation 3:

#### The EAG recommends a Hauora wellbeing approach to SUDI prevention that recognises and supports the importance of whānau/aiga centred programmes with Maori and Pacific frontline workers in the context of wider environment of deprivation.

**Leveraging work to date**

The Hauora wellbeing diagram below provides a high-level depiction of the range of factors identified as influences in the death of an infant while sleeping and the development of a wellbeing Hauora wellbeing approach to SUDI prevention. Much of what we are currently doing in SUDI can be immediately mapped across to the SUDI prevention ecosystem. Antenatal care and education in wānanga, and specific health messages and for whānau Māori and aiga Pasifika are important. We are aware that *Hapū Wānanga* is an excellent and well established kaupapa Māori model of antenatal education and that this should be extended as widely as possible. The *Te Whare Pora* model which uses weaving to engage pregnant women in community and health networks is under development. A Pasifika pregnancy and parenting programme, *Tapuaki*, was previously developed as an approach to maternal and infant care incorporating SUDI prevention but changes in investment could not ensure its sustainability and this should be rectified. Similarly for smoking cessation, a difficult task to undertake in the best of circumstances, the funding of innovative Māori focussed programming like the *Kairua* programme is appropriate.

### Recommendation 4:

#### The EAG recommends programmes that are culturally anchored for Maori and Pacific families, enable solutions that are whānau/aiga led and are delivered in genuine partnership with the appropriate community based providers.

# Conclusion

The Expert Advisory Group acknowledge all the strategies to date that have led to the successful reduction of SUDI in New Zealand over the last few decades. Raising awareness of SUDI risk and protective factors, education programmes for carers and the health workforce, safe positioning of infants, provision of infant sleep devices and smoking cessation programmes, have and should continue to be, important aspects of ongoing SUDI prevention investment and programmes.

The new factors revealed by this review of sudden infants deaths over the 2019-2020 period are a toxic combination of financial insecurity, housing poverty, exhausted parents of concurrently unwell infants - the mother of whom smoked in pregnancy, who made the ill-fated decision to bedshare with their infant on the night of the death. It is not shown by the review data whether that bedsharing was habitual or was a decision made around the unwellness of the infant.

It is this wider knowledge around the circumstances of death, the ongoing lack of any decline in mortality and the persistent 6-9 times disparity in the sudden deaths of Māori and Pasifika infants that lead us to recommend a profound change of approach to SUDI prevention. Changing from an infant care practice risk-based approach targeted at individual carers in the above circumstances to a cross-sectoral support network for whānau encompassed within a wider child and family wellbeing framework is now essential.

On the basis of this contextual thinking around the SUDI deaths in NZ and the data founded in the Taylor & Foaese report, members of the Expert Advisory Group recommend that the Ministry of Health:

* works in a cross-sectoral fashion with other Crown Ministries to mitigate the adverse social determinants of health that contextualise SUDI deaths
* trusts and resources Māori and Pacific leadership to take control of a single SUDI prevention programme
* take a Hauora wellbeing approach to SUDI prevention that is encompassed within a wider child and family wellbeing framework
* ensures values-based, culturally anchored, community partnership, whānau-led approaches for engaging and working with families.

Collectively championing infant safety requires knowledgeable, passionate and charismatic leadership with the strategic acumen to draw all these groups together and to advocate meaningfully in a range of forums and contexts. We wish the Ministry well in effecting the required change in amongst all the concurrent changes in the health sector presently. Leadership is required here and we urge the Ministry to take advantage of what we all recognise as a Māori and Pasifika SUDI prevention network that is well able to do the job.

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# Appendix 1: Hauora – a wellbeing approach to SUDI prevention



# Appendix 2: The SUDI Expert Advisory Group

The Ministry of Health’s SUDI Expert Advisory group is made up of a number of workers in the early childhood sector including primary care, public health, antenatal care, smoking cessation, the Coronial service, Māori and Pasifika health promotion and policy workers, SUDI researchers and was supported by Ministry of Health and National SUDI Prevention Service personnel. They were called together in February and March of 2021 to consider the findings of an analysis of the Coronial SUDI Liaison Reports of 64 infants deaths (provisional) that occurred between July 2019 – June 2020.

### The EAG

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| --- | --- |
| Professor David Tipene-Leach | Professor of Māori and Indigenous Research, Eastern Institute of Technology |
| Alayne Hall | Co-chair of the National Child and Youth Mortality Review Committee, Senior Lecturer-Research Fellow, Auckland University of Technology  |
| Professor Ed Mitchell | Cure Kids Research Professor |
| Elaine McLardy | Communio SUDI Liaison Officer, South Island |
| Kate Nicoll | Community midwife and SUDI Prevention  |
| Kelly Spriggs | Whānau Āwhina Plunket,  |
| Koha Aperahama | Nurse and Antenatal Educator, Northland DHB  |
| Tania Tetitaha | Coroner (Whangarei) |
| Christine McIntosh | General Practitioner, Chair of the Counties Manukau Child and Youth Mortality Committee.  |
| Heather Muriwai | Counties Manukau DHB Clinical Lead Advisor, Midwifery |
| Jacinta Fa'alili Fidow | Director, Moana Research |

### Ex-officio members of the EAG

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| --- | --- |
| Professor Barry Taylor  | University of Otago, commissioned by the Ministry of Health |
| Rachael Hetaraka-Gotz | Ministry of Health |
| Anna Foaese  | Ministry of Health |
| Josette McAllister | Ministry of Health |
| Faye Selby-Law | Hāpai te Hauora |
| Nari Faiers | Hāpai te Hauora |