Report prepared for the Ministry of Health

Report on Hui on the development of a National Safe Sleep Programme

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sapere research group

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Executive summary

Number and purpose of the hui

The purpose of the hui was to gain expert and local knowledge of what works well and what people believe is a way forward for the future. In total, five hui were held: three face to face, one by videoconference, and one by teleconference. The Wellington hui was by videoconference due to postponement because of the Kaikoura earthquake.

The attendees were generally a mix of health professionals, weavers (for wahakura), and there were some families (mothers) in one hui.

Key themes

The key themes across all the hui were:

- **Invest early** – healthy pregnancies are important; invest in antenatal care.
- **Smoking** – prevention and cessation. People overall were very strong that smoking is the biggest risk and therefore more investment, particularly for Māori women, is very important. In addition, the modes of delivery of anti-smoking messages need to be broader.
- **Breast-feeding** messages are important and supporting mothers to breastfeed is important.
- Consider each whānau in their **own context**. Each situation is different and must be considered.
- Note the **changing social context** – e.g. with more families sleeping in cars.
- Must use a **whānau ora approach** for all families – take into account all people who may (a) influence or give sleep messages to the mother, and (b) may be at the time the babysitter for the infant.
- **Poverty** is a great risk – not just SUDI risks. For example, poverty related issues such as housing, heating, dampness, transport options, etc. Is there a way of working cross-government to help address this issue?
- Need to **use resources innovatively** – the way the **workforce** works (i.e. be more generalist to address all needs they see with a family, in a home, etc.).
- We need more **evidence** – as trends and knowledge changes, we need additional evaluations to see what is really working/making a difference. This for both **data and evaluations**.
- There needs to be **investment in time** for frontline staff to spend time with whānau, building trust and relationships, so the hard conversations and the messages can be heard.
- Note that although **pepi-pods and wahakura** are one option for safe sleep, they are not for everyone. However, they are a vehicle to open up communication channels. **Target and prioritise** funding for these, as not everyone needs them.
- In addition, for safe sleep surfaces, consider the **size of the baby** and what is the next safe sleep option after a pepi-pod or wahakura.

- Better use of **cross-government resources** – needs to be managed and reduce invasiveness for families, but also to use resources more wisely.
- **Simplify the safe sleep and risk messages** and provide these in a variety of mediums. Provide **consistent messaging**, as they can contradict each other currently.
- Transparent **transfer of care** is very important to ensure accountability.
- **Longer-term contracts** for providers (i.e. not one-to-three years) are important so they can plan and invest in the services. Note also, to foster and create cultural and intergenerational change means longer-term contracts are needed.

1. Purpose and methodology

1.1 The Hui were to get expert and local input on priorities for a National Safe Sleep Programme

In total, five hui were held. The Wellington hui was postponed due to the Kaikoura earthquake and was rescheduled for the following week. An additional hui was held, as the original week of hui clashed with the Paediatric Society conference and so many could not make it. In total, 122 people participated in the hui from a wide range of backgrounds, NGOs and health providers, professional roles, lived SUDI experience, and other than Health Ministries.

Invitations for the hui were sent out to identified organisations by the Ministry of Health (MoH). All but one of the hui were opened by Nohopuke Williams from the Ministry of Health. Sapere facilitated all hui and were responsible for recording the notes and themes.

The following table details the locations dates and numbers attending for each hui.

1.2 Summary of dates and locations

Table 1 Hui dates and locations

Hui Location	Date (2016)	Attendance	Venue
Christchurch	16th November	11	Sudima Hotel, Airport
Napier	17th November	36	Crown Hotel
Auckland	18th November	42	Cliftons Conference Centre
Wellington	23rd November	17	Ministry of Health/Video conference
National (paediatric)	24th November	16	Teleconference
Total attendees		**122**	

The notes of each hui were analysed for themes and from there this report was written.

2. Christchurch hui

2.1 Attendance

This hui was on the 16th November 2016, and was two days post the Kaikoura earthquake. Eleven attendees were at the Christchurch venue and covered a range of disciplines such as breastfeeding advocates, lead maternity carers (LMCs), district health board (DHB) planners, researchers, and non-governmental organizations (NGOs). The attendees noted they thought that Plunket not being invited to the hui was a gap.

2.2 What Canterbury is doing now

Although this was not an express question at the hui, there were various examples of what Canterbury is doing for safe sleep now. These examples are included with the caveat that there are likely to be additional examples, which were not canvassed.

- South Island safe sleep policies, education, and resources.
- Canterbury-wide safe sleep pathway to bring all resources together.
- Audit (risk assessment) process for high-risk situations.
- Giving out pepi-pods.
- Post-earthquake (2011) strong safe sleep messages, wahakura, breastfeeding, and non-smoking messages.
- Research and health promotion underway.
- Work with families in their own context.
- Have a variety of providers, but resources are stretched.
- Children's Teams are doing inter-sectoral work.
- Well Child Tamariki Ora quality improvement project underway (this is being presented at the Integrated Care Conference in November 2016).

2.3 Key themes

2.3.1 Variance in opinion of how to develop and deliver a safe sleep programme

People felt the variance in opinions of how to develop a safe sleep programme, is largely driven by researchers' needs to focus on their narrow research topics and not look broadly. Therefore, people in general get different opinions.

2.3.2 Priorities and what is important to reach families and assist with safe sleep messages to be sustainable

More investment needed and educate early

It is important to invest early, that is before pregnancy. Overall, an important thing is to foster healthy pregnancies and that will assist with reducing SUDI risk factors post-birth. The hui called for government to invest more into pre-pregnancy education and to invest more resources into allowing more time to be spent with women and families. Funding models need to reflect an outcome model.

There was a call for more co-ordination across the sector and, importantly, to ensure consistent messaging. It is evident that there is currently inconsistent messaging and women report that they are confused. This messaging is by providers and at times the wider family, as there are inter-generational experiences of how a baby should sleep.

Support for breastfeeding is important

A strong message from this hui was the importance of breastfeeding and supporting women in this.

Education for women must be meaningful for them

Women need to know what is available. They also need to know and understand about safe sleep spaces. Education and information needs to be evidence based. Information needs to be in the context of the family and must be culturally appropriate and accessible. For example a simple "Safe Sleep" sheet. Mothers and families must be able to make informed decisions.

A holistic whānau ora model is needed; building trust and relationships vital

A safe sleep programme must be whānau focused and not just working with the mother. It is important to get the safe sleep messages to wider family, and others who may "baby sit", so there are consistent safe sleep practices. The approach needs to be multi-pronged and use data and research to inform it. More resources are needed to ensure time can be spent with families face to face, with follow up. It is so important to be able to go into the home, take the time, and show respect to build trust and relationships. When you are in the home, you get to know so much more about the family circumstances, what their priorities are, and where baby is sleeping, than you ever could if you were not there.

Because we do not have the resources to build these relationships with enough families, there is actually an information gap on the number of people whom bed-share with their babies.

Preventing and stopping maternal smoking is the greatest priority

Although all hui mentioned preventing and smoking cessation as a high(est) priority, the Christchurch hui were the most vocal about this. One participant even went as far as challenging the government to stop importing tobacco at all and that the Ministry of Health stopping smoking targets should be stronger.

Poverty is the greatest indicator of risk

Poverty was cited as the greatest indicator of SUDI risk, as the determinants of health that are challenged by poverty situations are typically the SUDI risk factors, e.g. smoking, heating, housing, family violence, etc.

Isolated and rural communities need an innovative approach

As there can never be enough resources to do everything that is needed, it would be positive to develop safe sleep "community champions" or "peers" who can be educated and deliver safe sleep messages locally. It is important that these people be respected in their communities, but it is not necessary that they be health professionals. It is important that they are paid and not seen as a "free resource".

More evidence is needed

Some of the strategies for safe sleep are relatively new and therefore research and evidence is not yet refined. Participants specifically mentioned evidence is needed on what strategies work best for Māori and Pacific families. This also includes what health promotion messages work best and how to deliver these.

2.3.3 Hard to reach or reach too hard?

The system needs to work differently and be more responsive

Health professionals and agencies working in this space say they need to take a step back and consider how best to reach families. It is not the families' issue that the messages are not getting to them; it is the way the system and the agencies work. Attention needs to be taken and given to those families that are transient and might have more than one or two complexities in their life.

2.3.4 What are the real problems we need to solve for a national safe sleep programme?

Poverty

Many of the hui participants regarded poverty as the biggest issue, as the determinants of health that are challenged by poverty situations are typically the SUDI risk factors.

The issues are multifaceted and complex, based on individual family circumstances

Each family's circumstance and needs are variable. As per the above section, it can be variable per family, depending on their need.

Top priorities: smoking prevention and cessation is the leading priority alongside breastfeeding education and poverty

The group was very clear that the following priorities, in order, to reduce SUDI are:

- Smoking prevention (whānau).
- Smoking cessation (mother and whānau).

- Fostering breastfeeding.
- Safe sleep surfaces.

Treating mothers and babies as separate entities is an issue

Previously mothers and babies were seen as one entity. Now they are seen as separate and it is believed this does not help with co-ordinating care and education messages.

2.3.5 Are there specific cultural successes and issues we can learn from?

Whānau in their own situation

The key message was that agencies need to work with individual families in their own situation and circumstance. This includes cultural considerations, but also important personal preferences and needs. Considering and incorporating these needs, as well as inter-generational messages, is a vital part of what needs to occur.

Whānau ora approach is vital

There must be a whānau ora approach ("it takes a community to raise a child"). It is not only up to the mother to raise a baby. All people who interact with the baby, and those who may give sleep messages to the mother, need to be involved in the education process.

2.3.6 What does all this mean for investment?

The hui was very clear that they, as a sector, need more investment to be able to spend more time, face to face in family homes, to:

- Build trust.
- Invest in relationships.
- See where baby is sleeping.
- Give meaningful messages to family, in the families' own context.

When asked about the magnitude of the required investment, this was not able to be given.

We need to change what we do and spend more time (face to face/in person) with mothers and families. We need to involve the wider family, especially grandmothers. At times, the messages from what grandmother used to do and safe sleeping now conflict and we need to educate.

Adding to business as usual without additional resources is not okay

As the heading says, adding extra roles and functions to business as usual jobs without additional resources does not make for a productive outcome for mums and families. There are competing challenges, including in what the contracts say and reporting requirements. These need to be aligned.

Working in an inter-sectoral way is important

Because many of the families we wish to target are involved with many agencies, e.g. housing, CYF, Justice, Health etc., we need to work better together. We need to make a plan about joint working and improving our communication.

Research/Evaluation

Does there need to be more investment into understanding what works best for SUDI prevention?

Where does accountability sit?

There needs to be discussion and agreement about where accountability sits. Individual health practitioners cannot ignore these families. Fathers, partners, babysitters, etc. all need to be included, and the health practitioners need to co-ordinate this.

2.4 What are the enablers to make a real difference

- Ensuring you work with the family in their own context.
- Stopping smoking and giving incentives for this.
- Peer support programmes.
- Involve the fathers.
- Health literacy.
- Reduce universal targeting (note: this was a competing message to doing a public health programme approach).
- Go into the home, have time, and have resource to build trust and relationships.
- Use the Safe Sleep Seven.[1]

2.5 Risks

Risks of proceeding with change were discussed. These included:

- The justice system and prosecution of mothers for SUDI – this will only force people to go "underground".
- Prosecutions will also stop the "real conversations" that need to occur.
- There needs to be more links between Treasury and the Ministry of Health to align priorities and funding.
- Engaging specific groups, e.g. gang groups. There needs to be specific people working in the sector, with dedicated skills for various scenarios.

[1] http://www.llli.org/sweetsleepbook/thesafesleepseven

- Trying to tackle too much at once – e.g. all the poverty and determinates of health issues. This also links to the ethical dilemma. If you try to solve all problems, but know you cannot, then from a health practitioner point of view there is a major ethical dilemma.

3. Napier hui

3.1 Attendance

This hui was on the 17th November 2016. There were 36 attendees from a wide range of organisations including health, researchers, NGOs, families, and weavers.

3.2 Key themes

3.2.1 Variance in opinion of how to develop and deliver a safe sleep programme

A key message was that the variance is typically due to varying opinions and lived experiences. In addition, that in different parts of the region varying opinions and resources are available to practicalities have to take hold.

3.2.2 What is important to reach families and assist with safe sleep messages to be sustainable

We need to be cognisant of why people do not come to appointments etc. "DNA" (i.e. do not attend) as is not an acceptable statistic. Why people do not come is the real issue, e.g. transport, competing demands, etc. Need to talk with and listen to people.

3.2.3 Hard to reach or reach too hard?

For a national programme and as health professionals, we need to be aware of the language that is meaningful to people as well as what influences the choices people make. Services and supports need to try harder to prioritise and reach people. Families are clearly saying do not give us the same "old messages" as they do not work. One thing that has seemed to work is the weaving of the wahakura – taking the time to sit with people, talk and listen.

Approaches and messages need to be given in a cultural context.

> *"Don't have 40 agencies in my life. This is overloading a whānau. Too many different messages – this is confusing."*
>
> *"I have 6 kids. I didn't know about any of these agencies till my last kid. And that was only because of the weaving [of wahakura]…"*

Agencies need to be better at how they communicate. A one-pager of visuals is better than a 20-page brochure. Also, information and data needs to be up to date.

Just saying, *"don't smoke in pregnancy"* does not work. Agencies need to work closely with people in their own context. They say they need to be clearer and give do not smoke messages in a variety of ways. A "one stop shop" approach to brochures does not work. There is some anecdotal evidence that showing mothers the effect on the oxygen in the baby's blood after a smoke does make an impact.

We need to adapt and do things differently – it is our issue, not the families. However, we need time to do this and currently there is not enough resource. We need to move from an individual approach to a whānau focus. We must never say, "*this is too hard and give up on people*". Many people feel they have been "*lied to before"* by "authority", so it is important to build trust and relationships.

3.2.4 What are the real problems we need to solve for a national safe sleep programme?

The Napier hui was very strong on Māori, wahakura use, alcohol use reduction, and anti-smoking. Also, using marae based education opportunities and to "celebrate the life". In addition, to target older generations as they influence the younger generations. Need an entire healthy pregnancy, well child, and whānau ora approach.

The issues are multifaceted and complex, based on individual family circumstances

As already noted, messages need to be in the families' own context. This includes cultural considerations as well as the multi-faceted needs and circumstances families have.

Top priorities: smoking prevention and cessation is the leading one

Discussion on the use of e-cigarettes (vapours). Opinion was that the e-cigarettes are much better for pregnant mothers than tobacco cigarettes and that the Ministry of Health should approve them for use.

In addition, discussion on use of incentives to stop smoking, e.g. payment for nappies and grocery vouchers for fathers. Attendees felt incentives worked and that there was international evidence of this as well. It is important not to have contradictory incentives.

Simplify the messages and make them consistent

There was a strong message that as a system, the safe sleep messages need to be clearer and simpler. Use of visuals on one pager was recommended.

We need to work smarter

There was a call to action for health professionals and cross-government agencies to work smarter. Why are so many people in one home when, if we worked smarter, there could be fewer, a better-focused and co-ordinated outcome for the family, and the limited resource we have to be used more wisely?

Invest in what really makes a difference

Looking forward it is important to invest in what makes a real difference. As listed, the priorities of smoking prevention and cessation etc., but more importantly the "how" of what is done, e.g. the delivery of the messages, early investment (timing), etc.

3.2.5 Are there specific cultural successes and issues we can learn from?

Yes. It is important to work alongside families and whānau in their own context, taking into account their preferences, priorities, and cultural needs. In addition, it is important to work in a whānau ora model – incorporating all the whānau for education and learning.

There was discussion on smoking and alcohol and it was noted that there are more smokers in the Māori women population than alcohol drinkers, so smoking cessation is more of a priority.

Could part of a national programme be a specific cultural Māori stop smoking campaign?

Also, we need to consider the advantages of more generalist training as opposed to specialist training. So that when a "professional" goes into a home, they can pick up and consider a range of whānau needs. We need to avoid the "40 cars in the drive" and take the opportunities as they arise. Take away the false (professional) boundaries.

It is vital to recognise the connection between spiritual beliefs and wahakura. This is an important vehicle to get the safe sleep message across to people.

3.2.6 What does all this mean for investment?

Lead Maternity Carers are too busy

There was a lot of information about the fact that the LMCs were often too stretched in terms of resources to do what needs to be done regarding parental education, spending time with whānau, etc. Investment in LMCs is important. Also, be careful to match workers to whānau needs, e.g. Māori workforce for Māori whānau. These people are becoming too burned out. We need a Marae based model, e.g. the weaving of wahakura.

There needs to be more investment in prenatal support and information

An early investment approach, with repeated messages, is thought to be worthwhile, e.g. smoking cessation prior to pregnancy. It is a bigger picture than just the pregnancy – it is whole of family/whānau health. A healthy pregnancy is what is important.

One suggestion was that there is a dedicated person for say the five per cent of families that are really hard to communicate with. If we had the "right" people with excellent skills, this would make a difference.

There is a disconnect between Ministry of Health and the "ground level"

There is a disconnect between what the MoH thinks and what the ground level knows works. Communication needs to be improved. Is there an opportunity to have an on-going "*group*", so that together we can make a difference?

Poverty is a major issue

Poverty factors, e.g. housing, heating, transport, and income, are significant issues affecting healthy pregnancies and safe sleep. That is the "*social determinants of health*".

Data is important

Scope, collect, and use data more wisely and proactively. This will assist with looking at the combination of risk factors. Is there an opportunity to connect GPs and others, with IT, to share data and information?

DHBs as fund holders?

Would it be a good idea for DHBs to be fund holders for safe sleep work / programmes? They may be able to know their local communities better and prioritise the use of funds.

Look at the data: impact on Māori as well as cultural audits

If you look at the data, then more investment needs to go in to Māori whānau and babies.

There should be "*cultural audits*" on how services are operating. Variance is okay, as there needs to be flexibility to reach different whānau.

A national campaign is needed

There is a need for nationally consistent messages and a national campaign. Use a variety of methods like TV, social media, Facebook, etc. This is very important to reduce the mixed messages whānau receive.

The current funding model for high risk DHBs does not work

A few years ago, MoH gave some DHBs funds for high-risk SUDI populations. In effect, this does not really work, as it is not population based funding.

Workforce

We need to use our workforce better. More co-ordination and "generalisation" is needed to ensure the workforce can work with families, e.g. housing, safe sleeping, nutrition, family violence, poverty, etc. Communication is key!

In addition, people and organisations like weavers need to be trained in safe sleep messages, as they have interface with women who may hear those messages. All opportunities should be taken to get safe sleep and healthy pregnancy messages across.

How can DHBs devolve funding to those who know how to make the difference?

A key question was how could DHBs devolve funding to those organisations who are working at the "*coal face*" with families, and who really know the needs of those families?

3.3 A national safe sleep programme logic

Simplify communication

This hui expressly addressed the question of a national safe sleep programme. There was general agreement on the need for quality information, presented simply and without jargon. The messages need to cater for the whole whānau. Whānau need the right information so they can make informed choices.

Investment in pepi-pods and wahakura is important. There needs to be a reprioritising of funding to ensure pepi-pods and wahakura can be funded – not for all families, but for those that need them/could benefit.

There is a need to resource LMCs more so they have the time to do what is needed for whānau. They need to be able to be responsive and be able to "connect things up".

Workforce needs to be supported and developed. They need to be non-judgemental and support families in their own context.

The way we measure in the future is really important

How we measure what is really happening for families is really important. We need to look at what our measures are and when we do them.

Local innovation is important, supported by nationally consistent messages

Different communities have different needs – and local innovation to meet this is important. There needs to be time to identify these successful innovations and then to share the learnings. To create change in health professional and NGO behaviour also requires a lead role from a national programme, with nationally consistent messages (reduce confusion for women). Lead champions, by the right people and in the right way, are important.

Consider what mediums and media are used – do not just use Māori TV.

Co-ordination and communication of services is important

From both a mother and health professionals at the hui, there was anecdotal evidence that there needs to be more co-ordination of all services to support families/whānau. A strong call for one "*lead*" person and they can co-ordinate everything the whānau needs.

Could a national programme consider how we get a network of safe sleep co-ordinators? This is not the whānau ora navigator, but people with additional education and skills in safe sleep.

We need to acknowledge and work with the changing social circumstances in New Zealand

When people are sleeping in cars, the messages and education for them needs to be different than for those in a house. More and more, we are seeing people living in cars. For example, the needs around temperature, health, and safe sleep surfaces are so different. We need to work well and differently with those in our communities who are of lower socioeconomic needs.

Invest in antenatal care

A lot of discussion is that antenatal care does not have enough investment and that is where the education (e.g. safe sleep, smoking cessation) could make the most difference.

4. Auckland hui

4.1 Attendance

This hui was on the 18th November 2016. There were 42 people in attendance. There was a wide mix of attendees such as nursing and sleep co-ordinators, midwives, service and portfolio managers, a GP, researchers, lactation consultants, stop smoking service, SUDI liaison people, weavers, manager of Whakawhetu, child mortality review people, a birthing centre manager, Health Start for Pacific people, Tamariki Ora services, Ha Pai Hauora services, a paediatrician, and lead maternity carers.

4.2 Key themes

4.2.1 Variance in opinion of how to develop and deliver a safe sleep programme

The key message was that lived and intergenerational experiences mean that people have varying opinions. For a National Safe Sleep Programme, this means that there is a need for nationally consistent messages, delivered in a variety of ways across a variety of mediums. Follow up and face-to-face in-home visits are very important and need to be resourced. Different DHBs do this differently.

4.2.2 What are the real problems we need to solve for a national safe sleep programme?

The issues are multifaceted and complex, based on individual family circumstances

It is so important to see whānau in their own context, and consider and respect their own circumstances. Everyone is different. Recognition of poverty and what this means for families on a day-to-day basis is important.

In addition, there are compounding factors for whānau that are not funded, e.g. food and transport (i.e. linked to poverty).

Top priorities: smoking prevention and cessation is the leading one

Smoking is the leading issue and we need better prevention and cessation programmes for New Zealand.

There is an opportunity for education about what babies need

There is an opportunity to put out holistic messages about what babies need, which includes safe sleep practices. This can also include other risk factors such as smoking, alcohol and drug use, plus the importance of breastfeeding. We need to focus on a message that "*smoking actually affects babies*".

Affordable and accessible health care is an issue

Affordable health care is an issue. Young mums are turning up at emergency departments as they cannot afford a general practitioner (GP).

Longer term funding and contracts give certainty

Funding is an issue. The short-term contracts are not conducive to designing and delivery of a long-term service. In addition to funding contracts, there is a potential for national standards around wahakura – as they are not all the same.

Need to work with Justice; prosecution is not the solution

Prosecuting mothers for the death of their baby is not a solution. Doing this will only make the conversations of safe sleep even more difficult, and for some impossible.

Communication/education mediums are important

Communication needs to be simple, put in plain language, and the use of graphics or pictures is good. Consideration of both Māori and Pacific mediums is important too.

4.2.3 Are there specific cultural successes and issues we can learn from?

It is important to support and foster our local initiatives. Generally, we know what our local whānau and communities need. However, more resource is needed to do this well, especially to have the time to do home visits and spend the time with whānau building trust and relationships.

4.2.4 What does all this mean for investment?

National consistent messages that get to everyone are important. This is about smoking, safe sleep surfaces – everything.

Certainty of investment (i.e. funding) is important. It is hard to go from year to year and not know.

Healthy pregnancy and mothers getting the right messages and care before pregnancy is vital.

Note that it takes time to realise benefits of investment – sometimes several years. It requires behavioural and culture change, which sometimes takes over six years.

5. Wellington hui

5.1 Attendance

This hui was held on the 23rd November 2016, and facilitated via video-conference. This date was a postponement from the original date, which was the day after the Kaikoura earthquake. Seventeen attendees were at the Wellington venue, representing a range of cross-sector organisations and disciplines. These included the Ministry of Education, Ministry of Health tobacco team, the local iwi health provider, hospital midwifery, Ministry of Social Development, and Child & Youth Mortality Review Committee (CYMRC).

5.2 Key themes

5.2.1 Risk of SUDI sits within the context of poverty and social determinants

It was identified that a common theme from the SUDI cases reviewed by a local Child & Youth Mortality Review Committee was the impact of poverty. The most vulnerable families face a number of significant challenges in their lives. We make common assumptions that there exists a lack of knowledge; however, when people talk to these families, often they do understand what the "right thing to do" is, and it is their circumstances that make it difficult to implement that knowledge.

One participant, from the Ministry of Social Development, offered that there is Work and Income support for young families and some of it is non-recoverable. The issue seems to be that people are unaware of the support available. The question was raised as to whether there were ways that other professionals (e.g. GPs) could approve small grants funded by WINZ. Now, that is probably not possible. A family might know they need a safe sleep space, yet if they are unable to afford one, then negotiating their way through the system to receive assistance becomes too hard. We need to remove the barriers to "doing the right thing" and rewrite the rulebook about who can do what.

The view expressed by the CYMRC representative is that one of the key things they would push is the need for the systems to change, rather than expecting families – who are managing complex and chaotic lives – to change.

This theme was summarised in two key challenges:

1. How can the system modify the impact of social determinants and ensure women have healthy pregnancies?
2. How do we protect babies within families who are already at very high risk?

5.2.2 Smoking prevention and cessation is the leading priority

Smoking came through strongly as an important modifiable risk factor for SUDI. Preventing young people from taking up smoking is important, and we should not wait to focus on pregnant women quitting. The ASH Year 10 survey was referenced, which shows the prevalence of smoking among 14-15 year olds has fallen dramatically. The age of initiating smoking has increased, with the challenge now to keep young people smoke-free until the age of 25 years. The rollout of plain packaging is expected to have more of an impact on the uptake of smoking, as opposed to an incentive to quit.

It was highlighted that around 43 per cent of Māori women currently smoke during pregnancy, compared to around 18 percent in the general population. This statistic for Māori has not changed markedly over some time. Quit smoking services have recently been re-contracted by MoH, with Māori and Pacific being the target population. Alongside this, there is another four years of tax increases on tobacco. The focus of MoH for the next year is why do young Māori women smoke during pregnancy and what would make a difference?

There was some discussion around nicotine replacement for pregnant women. Nicotine patches are currently prescribed to pregnant women and in some cases, an e-cigarette may be suggested. Nicotine is one of the things that sensitises a baby to SUDI risk; therefore, if we can reduce the dose using various replacement therapies, then that is important.

The group reflected on the value of pregnancy incentive schemes, citing the Counties-Manukau trial in which pregnant women received vouchers to quit smoking, along with incentives for support people. The pilot was part of the Pathway to Innovation fund and results quoted at the hui suggested that 58 percent of participants remained smoke-free at 12 and 24 weeks.

This type of scheme has recently begun in the Hutt Valley, where local providers are saying the biggest breakthrough has been the clinical measurement so the parent can see the impact of tobacco on their baby.

5.2.3 Creating a culture around safe sleep

A key theme emerging from the hui was the impact of inter-generational behaviours. For many women, the most significant influences in their lives are their mothers, sisters, grandmothers, and extended family members. Examples were shared of children brought up within a particular cultural context, where sleeping practices are based on the way things had always been done. When the messages parents receive from health professionals' conflict with their family and cultural practice, they tend "*do it anyway*" and in most cases it works for them. Advice to simply not bed-share is unhelpful; we need to work with parents and caregivers to make the environment safe and protect the baby.

It was suggested that thinking about safe sleep within a community development paradigm rather than individual health promotion could be useful. Parents would be part of a community of like-minded people that adopt the same practices, and share the same messages among each other. If messages are coming from an outside source, it often does not match people's own reality and they are less likely to be adopted. Getting iwi leaders involved as strong advocates is important.

The use of peers to deliver messages was raised, with a useful example of local peer support training around breastfeeding. It is important to note that this is not about a free workforce; rather, using the right people to deliver the right messages.

5.2.4 Collaboration across sectors

There are multiple agencies across different sectors that are involved with many of these vulnerable families; the issue is that no one has the complete picture. Agencies and professionals need to work together to support families and we do not want 'five cars up the driveway'. It was acknowledged that everyone struggles to negotiate funding barriers between inter-sectoral agencies.

The education sector is an important part of parenting education. It was noted that we should provide education before young women become pregnant. Examples of in-school education included Plunket's Tots and Toddlers programme. Many of these parents have not been exposed to good parenting themselves.

Reaching young people who are outside the school system is a challenge, both for parenting education before pregnancies occur and for antenatal. According to the Ministry of Education, a third of teenage mothers are not in the education system and therefore miss out on the protective system of school. There are multiple protective systems – marae are another example.

5.2.5 Trust and simplicity of messages are key

Making a connection and building trust is critical. As one provider noted:

> *"Our first 5 minutes is our 'in' – if we don't connect then it won't happen. We try not to push too much information on the first visit – it's more about relationship building"*

Relationship building is crucial so that parents and family members will tell you what is really going on within the household. It can be difficult to get messages across, particularly if parents have older children and think 'it worked last time so it will be fine this time'. It is also hard to convince people that SUDI is a real risk; it is a very rare event, so people can see unsafe practices around them and never know of a child dying.

A general comment was that messages are not simple enough. The Well Child Tamariki Ora book is thick and often goes unread (even by highly educated people). Health professionals deliver messages without visualising the space. The example was given of a family using a mattress on the floor propped up with pillows.

The language of clinicians can be complex, and does not get through to the people it needs to. In an example from green prescriptions, women said they did not want words; they wanted pictures, as they were overwhelmed by the information given during pregnancy.

5.2.6 Safe sleep devices are part of a holistic approach

Safe sleep devices such as pepi-pods and wahakura were discussed in the context of all the issues outlined above. Wahakura are considered a beautiful item, whereas the pepi-pod is "an ugly plastic box". The question was also raised as to what happens when the baby grows out of the pepi-pod or wahakura? Issues of funding came up as to how safe sleep spaces can be

funded, and how it is difficult for frontline staff to provide advice if they cannot offer a free pepi-pod or wahakura.

6. Paediatric hui

6.1 Attendance

This hui was held on the 24th November 2016, and facilitated via teleconference. It was an additional hui to provide an opportunity for people to provide input if they were unable to attend previous hui due to a clash with the Paediatric Society Conference. Sixteen people from a range of health professional disciplines attended the teleconference, from across New Zealand. Examples included CYMRC co-ordinators, a health equity manager, midwives, planning and funding managers from DHBs, public health nurses, injury prevention, and pepi-pod scheme managers. People thanked MoH for enabling this opportunity to have their input.

6.2 Key themes

6.2.1 Roles and responsibilities of different health professionals

There was discussion around the role of different health professionals, including:

- An example from Whanganui where the pregnancy and parenting co-ordinator is screening all the antenatal programme referrals to see who might benefit from a safe sleep device.
- The role of the LMC – they should be assessing the vulnerability of the mother and making those referrals. If it is not happening, then does more work need to be done with LMCs to make them more aware of available services/safe sleep spaces and be more proactive.
- There is a challenge around LMC midwives in terms of their resource and time availability. The section 88 funding mechanism was raised as an issue. There are specific deliverables required within the section 88 notice; however, there is a misalignment between that and the Well Child Tamariki Ora Schedule (WCTO schedule). Some LMCs are being guided by the WCTO book, rather than the birth to six weeks guidance under the section 88. The notice is under review and will hopefully become more meaningful in the future.
- Smoking is the key risk. We need better anti-smoking campaigns and messages.
- Important to tap into teen pregnancy education. One third of pregnant teens are not enrolled in any pregnancy or parenting education.
- Consider use of the Family Start programme. This programme is focusing on vulnerable families.
- Tasking a whānau ora approach is very important, including fathers and grandparents as well. (Note: other hui also included anyone who may be a potential babysitter.)

6.2.2 Creating a culture of safe sleep

Feedback from Child & Youth Mortality Review Committees is that when they interview families, LMCs, and WCTO providers, there has been lots of information given about safe sleep practices. Often people working with the families know that what they are being told is not what is really happening within the home.

Often the advice that the older generation passes onto their children and grandchildren differs from advice given by health professionals. One of the keys to behaviour change is getting the older generation involved, with the message that things change over time and 'it's okay that you did things differently'. Often the most important and influential people in a mother's life are their own mother, sister, nanny, etc. Therefore, it is important that messages are pitched to those people and groups, along with good reasons as to why we are promoting safe sleep.

It is also useful to take opportunities when family is present, e.g. on the post-natal ward, to provide safe sleep messages to the wider family.

6.2.3 What happens when baby sleeps away from home?

The issue was raised of baby sleeping away from the usual home or sleep surface, e.g. if the family is away from home for the night or weekend. When the baby is not in its normal sleep environment, the parents or caregivers may not have all the right bedding with them, or someone else has put the baby to bed (e.g. older siblings, grandparent). Being away from the usual place of sleep is inherently risky.

6.2.4 Creating sustainable change in safe sleep practices

An interesting point was raised in relation to the importance of emotional intelligence in delivery of messaging to create behaviour change. We are still working within a medical deficit model, whereas the marketing industry does this well – is there something we could learn? Similar to seatbelts in cars – "people just know" what to do, and we need to get to this place with safe sleep.

Multiple messages from multiple people

People need to hear messages multiple times from trusted sources. They also need the opportunity to discuss and question, particularly if they have heard conflicting messages.

An experience was shared of working with early childhood education centres, churches, community groups, and marae around safe sleep practices. What has been found is that often it is the first time they have had a chance to discuss the issues. For example, if bed sharing is not acknowledged, then you cannot move past into why it is an important risk factor. A useful example from the Tongan community was one where parents had seen a positive difference in their children's behaviour if they co-slept, so had their own evidence that bed sharing has benefits.

People rely on their own lived experiences, often including frontline health workers themselves. Messages need to be from multiple trusted sources, e.g. GP, and Kaumatua, and be consistent. Peer support, i.e. trained locally trusted people, can be very powerful. Use the wahakura and pepi-pod as useful vehicles for people to deliver their messages.

One person referred to the importance of routine for babies and that this should be included in safe sleep messaging.

The role of safe sleep spaces

Participants from Whanganui shared their experience with very positive responses from young Māori mothers, and they now have people coming to them asking where they can get a pepi-pod from.

The issue of a space that grows with the baby was raised; however, the advice given to parents is that once babies are able to move for themselves, they need to be in their own bed (usually around five to six months).

In another example from Bay of Plenty, a wahakura wananga programme was implemented where mothers came and wove their wahakura. Coupled with the weaving and safe sleep advice was other education around nutrition and smoking. The mothers that attended the programme were all self-referrals, following advertising via Facebook, radio, and through LMCs. All of the women that attended the programme remained smoke-free for three weeks postnatal.

Start safe sleep messages early

One example from Southland was that they are implementing a short video and messages to children in early childhood centres about how to safe sleep their dolls. It is envisioned these messages and practices will remain with those children (both genders) through to their own parenting days.

It is also important to start early with non-smoking messages. It appears pregnant mothers are seeing advertising and other media that smoking means small babies and therefore easier births. This needs to be balanced with the health of the baby and risks messages.

Incentives can work

Two examples of incentives that have been used included giving butcher vouchers (as it is thought that if they are given grocery vouchers, they can be used for cigarettes and alcohol) and pamper packs for the mother. An alternative incentive might be to give nappy vouchers for mothers to stop smoking.

6.2.5 Transfer of care is important

There was some discussion on the transfer of care between health professionals and the greater opportunity for communication and identification of risk. There were numerous examples (across all hui) of transfer of care not taking full accountability. For a national programme, there needs to be a "pathway" or some co-ordinated form of "transfer of care" where someone/an agency has responsibility for the oversight of the baby and mother.

For example, for a woman and baby moving towns, there should be a WCTO provider notification so the new provider can triage for risks and any need for home visits.

Currently, another lost opportunity is when women and baby go to hospital; the WCTO provider should get a discharge summary, and then they can triage for home visits from there.

6.2.6 Presentation to hospital is an opportunity, as well as other trusted sources

Discussion was held on poverty, determinants of health, family living circumstances, and family violence, etc. One clear opportunity is that when people present at hospital, e.g. emergency departments, there is a clear opportunity to screen for baby safe sleep. This will require training of emergency department staff in the future.

In addition, attendance at the postnatal care/ward is another opportunity. We heard that health professionals sometimes do not like to give the safe sleep messages, as they feel it can compromise the relationship they have built with the family.

The other opportunity is to target babies and families who are in the neonatal intensive care units. They are a "captured audience" and have babies that are at high risk of SUDI.

6.3 Summary

It is important to have a non-judgemental approach to working alongside families. The impact of inter-generational behaviours is considerable and therefore education and campaigns need to take a whānau ora approach. People and whānau need to be recognised and respected in their own context, so that safe sleep messages are meaningful to them. We need the right people in the jobs to do this – not one size fits all.