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**Māori Whānau Stories of Neonatal Intensive Care Units**

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MĀORI WHĀNAU STORIES OF NEONATAL INTENSIVE  
CARE UNITS**



**MĀORI AND INDIGENOUS ANALYSIS LTD.  
&  
RAUTAKI LTD.  
2010**

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## **Ngā Mihi**

E ngā iwi e ngā reo e ngā kārangatanga maha tēnā koutou katoa.

E tika ana kia mihi atu ki ngā mate o te wā, ki a rātou mā kua mene atu ki te pō, te pō uriuri, te pō tangotango, te pō e kore e kitea. Nō reira e ngā mate, haere haere, haere. Moe mai rā, okioki atu.

Ka huri ki a tātou te hunga ora, ngā ōhakī o ngā mātua tūpuna. Tēnā tātou katoa. He mihi mutunga kore tēnei ki a koutou ngā ringa rehe, ngā puna kōrero i whai wā ki te whakaputa whakaaro, kōrero mai mō tēnei kaupapa huhua.

Ki a koutou hoki ngā kaiāwhina, kaitautoko i te kaupapa nei mō tā koutou manawanui kia tūtuki pai ai tēnei mahi rangahau, tēnei rā te mihi ki a koutou.

Tēnā koutou, tēnā koutou, tēnā koutou katoa.

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## Executive Summary

### **The Project**

The research focuses on the kōrero of whānau Māori and provides narratives of their experiences as a means by which to provide insights into the needs of whānau Māori and their babies within the mainstream context of hospital neonatal intensive care units.

The methodology that informs this research project is that of Kaupapa Māori research, which locates Māori understandings as central to the research process and analysis.

The key research method is that of qualitative interviews which will be informed by the notion of 'Pūrākau' as a distinctively Māori narrative approach to engaging peoples understandings and experiences.

The research project includes a literature and data review and 30 interviews kanohi ki te kanohi in both a one to one and whānau context.

### **Literature Summary**

While it is unclear from Ministry of Health reports how many Māori babies entered NICU, Māori women and infants continue to be over represented in statistics related to infant and perinatal mortality.

Despite the plethora of international research literature about NICU, research about NICU in New Zealand is much smaller, and studies focussed on Māori and NICU are scarce.

Factors that contribute to this stress include an operative birth or emergency delivery, premature delivery and the experience of parenting a preterm infant in NICU.

While the reduction of stress caused to babies in NICU is carefully considered in much of the literature, there is also a large body of research that focuses on identifying and addressing the stressors of parents brought about by their babies being in NICU

Literature cites parent-infant attachment issues, depression and perceived lack of partner support as possible PTSD symptoms for parents of NICU babies.

The literature highlights that research is primarily related the experiences of mothers and babies, with a limited amount of research related to fathers experiences however it is clear that research is focused on the narrow definition of family as a heterosexual nuclear two parent family structure.

Literature highlights that positive family-centered relationships with providers, in particular the nurses, creates a context where families are more satisfied with the care received and report higher levels of psychologic well-being.

Despite the importance of family to the wellbeing of the hospitalised infant and their family, policies regarding family visiting NICU is not uniform.

International research demonstrates the faithfulness of parents in visiting children as much as possible, and the benefits of unrestricted visiting by family and friends of children in hospitals, however there are a range of barriers to unrestricted parental presence in NICU.

Nurses are usually the main source of information and facilitate appropriate services; moreover, nurses are identified as key in relieving stress for the babies, their parents and families.

The NICU environment, filled with medical and technical equipment, is foreign and restrictive to most families.

The inability to participate fully in parenting and relinquish much of the control to health professionals creates anxiety and a high amount of stress for babies, parents, caregivers and families.

The effort of nurses and other staff to practice a family-centred approach that also encourages interventions such as kangaroo care and breastfeeding can help mothers and families cope and feel supported.

While it is difficult to locate research that had focused on Indigenous peoples experiences of NICU, it is apparent that there are many commonalities associated with neonatal births amongst Indigenous women.

Indigenous women experience poorer birth outcomes high infant mortality, higher rates of low-birth weight and pre-term births.

A study of newborn care of Indigenous people of Australia, Canada, the United States and New Zealand recognises that each of these groups have lower incomes, poorer education outcomes, poorer food security, lower home ownership, and limited access to health services as compared to the non-Indigenous populations in their respective countries.

In Australia, Canada, and New Zealand, indigenous postneonatal mortality is higher than neonatal mortality.

New Zealand statistics confirm that Māori follow the pattern of poor maternity outcomes and newborn care of other Indigenous peoples.

For Māori infants, the major causes of hospital admission (apart from healthy live births) were perinatal conditions and respiratory disease.

Perinatal conditions (premature birth in particular) and sudden infant death syndrome (SIDS) were major causes of death among Māori infants. (ibid.:34).

Research highlights that 'health inequities' experienced by Māori should be understood in relation to our colonial history but how resources, including health services, are distributed to the community.

Research highlights that unequal health outcomes can be viewed as a result of environmental factors that impact on health and shape inequalities between groups, such as, racism.

A study that provides an example of ‘differences in the quality of care showed Māori receive poorer care than Pākehā in state-funded hospitals.

Research highlights that Māori families described feeling vulnerable in health service, their knowledge of their children often overlooked or dismissed because they were not the health professional, and there was a tendency to minimise the severity of the illness of their child.

Research has identified four broad dimensions important for Māori women and their health: connecting through whānau; nurturing wairua; using matauranga; and undertaking self-care activities.

It is noted that literature about Māori maternity consistently highlights the importance of: cultural safety, whānau oriented services and access to Te Ao Māori childbirth resources.

Research highlights that Māori mothers and whānau, are more likely to feel in control and empowered when there is positive communication and inclusion in the birthing process, regardless of any medical interventions that may occur.

The only research undertaken directly related to Māori whānau experiences in NICU shows that while whānau felt confident about the medical expertise and technological care their children received, the relationships that were formed with staff and others had a huge impact on how they felt at NICU.

It was found that when whānau were unable to actively support, mothers found that support from others such as parents who had similar experiences, were helpful in lessening the stresses of being away from their whānau.

There are various New Zealand frameworks aimed at promoting wellness, including Māori well-being, that have been officially accepted and implemented. The study undertaken about Māori whānau and NICU related to a lack of cultural understanding and highlights a disjuncture between practice and policy.

### **Interview Findings**

Whānau were highly appreciative of and acknowledged the clinical care received within the units.

Numerous comments were made in regards to whānau wanting to support the medical care and interventions being made by the staff for the wellbeing of their babies.

Where whānau acknowledged the medical care, often in the same discussion there would be clear issues raised in regards to social and cultural interactions within the units.

Key concerns were raised by whānau in regards to the overall culture of the units.

It is clearly identified that for those whānau that identified as Māori there were many issues and situations that arose for them that created additional stress during their involvement within NICU.

The following key themes were identified by whānau as key areas of comment or concern.

- Reasons for entering NICU
- Bonding
- Separation
- Accommodation
- Isolation
- Whānau
- Staffing
- Communication
- Tikanga Māori
- Need for Māori Support
- Impact on the home

A wide range of medical reasons were given by whānau for entering NICU, however the majority of the whānau interviewed were there primarily due to premature birth of their child/children.

A high proportion of whānau experienced emergency caesarean births, were induced due to health issues whilst a small number of whānau experienced early labour.

A high number of caesarian sections amongst participants meant that mothers were often dealing with healing themselves whilst experiencing the added stress of having a critically ill baby/babies.

Many whānau stressed the difficulty in bonding when their baby/babies were in incubators for periods of time.

Many mothers noted difficulty with breastfeeding and some commented on the pressure of trying to express in the NICU setting.

Some mothers highlighted the contradictions in being told to breastfeed but finding that when they went to feed that their babies had already been tube fed.

Bonding with babies was further exacerbated by separation.

Restrictions on whānau entering the unit also acted as a barrier to being with their babies, as did some of the treatment that whānau received from some staff.

Whānau experienced high levels of anxiety through separation not only from their baby but also from each other.

Lack of or limited access to accommodation contributed to the sense of isolation and separation felt by whānau.



Whānau that had access to parent rooms expressed less stress associated with being separated from their baby/babies.

The experiences of separation led to a number of whānau referring to feeling isolated within the Unit.

Neonatal Intensive Care Units operate on the construct of the nuclear family, which is fundamentally defined as two (heterosexual) parents and biological siblings.

A key issue raised by Māori participants was the need for a greater acknowledgement and involvement of whānau.

It was highlighted that many NICU staff need a greater awareness in what constitutes whānau.

Māori lesbian led whānau noted that they experienced additional difficulties in having some staff acknowledge their whānau structure.

Whānau were clearly aware of the need to ensure that medical staff were not impeded in their provision of clinical care.

Many whānau wanted to be active in the care of their baby/babies and where this was encouraged by some staff it was discouraged by others.

Whānau were aware of the primacy of the safety of the babies and in particular the potential for illness entering into the units.

Whānau actively sought to support and provide information to other whānau in the unit.

Whānau working together was a key support system within NICU.

Whānau had varied experiences with medical and support staff in the units.

There is a clear recognition by whānau of the generally high level of clinical care provided by staff and the need to be enabling of NICU staff to do their job.

Access to Parent Support people and resources provided whānau with additional support and information.

Both positive and negative interactions with staff were highlighted by whānau as significantly influencing their overall experience within NICU.

Negative interactions with staff increased whānau stress within NICU.

Appropriate communication between staff and whānau, and being able to access information were key areas raised by whānau.

Communication between clinical teams and whānau during rounds was also raised as a key issue.

A number of whānau commented on incidents within NICU that were grounded upon assumptions by staff about how them and the need for greater communication and openness.

Tikanga Māori was important for the majority of whānau.

Whānau noted that their ability to practice tikanga as mediated by the attitude of staff with a positive knowledge and approach making it easier for whānau to include tikanga in unit.

Few staff had knowledge of tikanga and te reo Māori.

A lack of te reo Māori also meant some staff had difficulty, or would avoid, pronouncing Māori names.

Very few whānau received any direct contact with Māori staff.

The lack of Māori clinical and support staff was raised by a large number of whānau.

Having a baby/babies in NICU often places considerable stress placed on the home context.

Older children, distance to the hospital, work and financial requirements can mean that whānau support is stretched and placed under additional stress.

Whānau that had long term stays in NICU talked of the difficulties of holding their jobs and maintaining homes.

## Introduction

In the Auckland District Health Board area around 900 infants are admitted annually to NICU of which around 160 have a birth weight of less than 1500grams.<sup>1</sup> National Womens Hospital 2006 report documented 118 Māori babies admitted into NICU, with the highest proportion being preterm.<sup>2</sup> It is also noted that there was an increase in 2006 of the number of stillborn Māori babies and neonatal deaths<sup>3</sup>.

The premature birth of babies is a highly stressful and tense event for whānau. The care of such babies is focused within hospital based Neonatal Intensive Care Units (NICU). Anecdotal evidence indicates that Māori have high admittances into such units and yet information from a cultural perspective is not readily available to whānau who find themselves in this situation. This research project investigates the experiences of Māori whānau who have had their baby/babies admitted to NICU in Aotearoa.

The research focuses on the kōrero of whānau Māori and provides narratives of their experiences as a means by which to provide insights into the needs of whānau Māori and their babies within the mainstream context of hospital neonatal intensive care units. The project was designed to provide an opportunity for whānau to share their stories about their experiences as a means by which to help inform both the organisations that provide Neonatal Intensive Care services and to share their stories with whānau who find themselves in a similar situation.

This report provides a series of ten narratives of whānau experiences and gives an analysis of both the literature and key interviews related to the experiences of thirty whānau who have had babies in neonatal care. What is clear is that NICU provide essential clinical care for many whānau who have babies in critical care, and that the survival of those babies is highly dependent upon the medical expertise of staff and experts associated with those units. However, it also raises key issues in regards to the social and cultural experiences that those whānau face during their time in the units. It is the hope of both the whānau and the research team involved with this project that these insights will support those in charge of such units to look at mechanisms by which these issues may be resolved in order to ensure the experiences of whānau in the future is much more conducive to the overall wellbeing of all involved.

## Methodology

A Kaupapa Māori research methodology was employed for this project. There are a range of elements noted within Kaupapa Māori that are of direct significance to this project, in particular; tino rangātiratanga, whānau, whakapapa, taonga tuku iho, te reo, tikanga<sup>4</sup> are all elements that are critical to the research approach in that each of this

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<sup>1</sup> //www.adhb.govt.nz/newborn

<sup>2</sup> At this point the researchers are cautious with these numbers as there is no indication as to how ethnicity is determined within the statistical data provided. Refer National Women's Annual Clinical report 2006: 229

<sup>3</sup> ibid:157

<sup>4</sup> Mead, L. T 1997 Ngā Aho o te kākahu mātauranga: The multiple layers of struggle by Māori in education. Unpublished PhD, The University of Auckland; Pihama, L. 2001 *Tihei Mauri Ora*:

elements are directly linked to the overall positioning of childbearing, childbirth and children – each of which are central to the issues at hand. The methodology that informs this research project is that of Kaupapa Māori research, which locates Māori understandings as central to the research process and analysis. Kaupapa Māori Research is a growing field of discussion amongst Māori researchers. This was highlighted at the Te Oru Rangahau conference where a vast array of papers were delivered in regard to research issues for Māori.<sup>5</sup> Graham Hingangaroa Smith notes that Kaupapa Māori theory and research must engage at both a culturalist and a structuralist level thereby ensuring that both micro and macro level engagement.<sup>6</sup> In her seminal publication ‘Decolonizing Methodologies: Research and Indigenous Peoples’,<sup>7</sup> Linda Tuhiwai Smith highlights that there is a critical political project as a part of Kaupapa Māori Research which is to develop Māori centred, defined and preferred ways of research and also which seeks to intervene in our historical experiences of colonisation. Other elements within Kaupapa Māori Research relate directly to the affirmation and validation of te reo Māori me ōna tikanga. Kaupapa Māori Research alongside its theoretical counterpart Kaupapa Māori Theory have at their centre the validation and affirmation of te reo Māori me ōna tikanga. This provides a foundation from which we as Māori researchers and academics can locate ourselves, and which supports a desire to research and theorise the world from our own understandings. What it states is that there are clearly Māori ways of exploring and conceptualising issues that face us as Māori people. Kaupapa Māori Research carries particular cultural expectations. Those are based within fundamental notions that are expressed through tikanga Māori.

As a Māori research team we seek to participate in transformative research in ways that affirm and validate Kaupapa Māori. We consider this research project is a part of that wider Kaupapa Māori research agenda in that we are seeking to make a positive contribution to the ways in which whānau Māori understand and experience Neonatal Intensive Care. This aligns with the idea expressed by Moana Jackson in his paper to the Te Oru Rangahau conference that “we reclaim. for ourselves, our own reality” and that we conduct research that will support us to “create a vision of hope for our mokopuna”.<sup>8</sup> Graham Hingangaroa Smith also relates to this vision in regard to Kaupapa Māori Theory. Drawing and expanding on the Habermasian notion of ‘utopian vision’ Graham argues for Māori to engage notions that support emancipatory outcomes.<sup>9</sup>

A Kaupapa Māori approach to the positioning of babies within Māori society may be seen in the construct ‘He Taonga Te Tamaiti’. According to Rose Pere<sup>10</sup>, Māori children are both adored and revered within tikanga Māori. The researchers hold also

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*Honouring our Voices: Mana Wahine as a Kaupapa Māori Theoretical Framework.* School of Education. The University of Auckland, Auckland

<sup>5</sup>Te Oru Rangahau was a Māori Research Conference hosted by Māori studies of Massey University, Palmerston North. see Te Pūmanawa Hauora 1999 *Proceedings of Te Oru Rangahau: Māori Research and Development Conference*, School of Māori Studies, Massey University, Palmerston North

<sup>6</sup> Smith, G. 1997 *The Development of Kaupapa Māori: Theory and Praxis*. Department of Education. The University of Auckland, Auckland.

<sup>7</sup> Smith, L.T., 1999 op.cit.

<sup>8</sup> Jackson, Moana 1998 in Te Oru Rangahau Proceedings op.cit.

<sup>9</sup> This will be discussed in more depth in relation to Kaupapa Māori Theory in Chapter Four

<sup>10</sup> Pere, Rangimarie Turuki Rose 1997 *Te Wheke: A Celebration of infinite wisdom*. (Reprint) National Library of New Zealand, Wellington

to the view that tamariki Māori are of major importance and that any and all research related to the wellbeing of our tamariki must have that notion at its centre. This is also in line with the notion that we must as researchers move away from deficit understandings and explanations of Māori health. This has been argued strongly by a range of Māori researchers.<sup>11</sup>

It is important to note that whilst this research engages with statistical data in order to ascertain the level and type of Māori involvement within NICU around the country it is not a piece of clinical research. It is research focused upon the experiences of whānau Māori and how they deal with the issues that may arise for them within the medical context of NICU. Having said that, all statistical data relating to the area has been explored and analysed by the research team from a Kaupapa Māori theoretical approach. This necessitates a critical view of the way in which data is gathered and presented within a range of national and regional health statistics, and requires that the team look beyond individual data sets to contextualise that data within a wider whānau, social, cultural and economic framework.

The key research method is that of qualitative interviews which will be informed by the notion of ‘Pūrākau’ as a distinctively Māori narrative approach to engaging peoples understandings and experiences. The power of such an approach in the area of childbirth and care is shown in research such as that undertaken by Helen Mountain Harte who interviewed a range of kuia about their birthing experiences both at home and in hospital. What is clear is that the hospital experiences meant much less ability to control ones own birthing experiences and practices.<sup>12</sup>

A pūrākau approach is a culturally defined narrative form currently being articulated by Māori educationalist Jenny Lee in her doctoral studies. This approach is aligned to the notion that Māori stories and histories are sourced within specific culturally defined forms of expression and that such expressions are multiple dependent upon whānau, hapū, iwi, contexts. For example, creation stories are not, as we have been lead to believe by early ethnographers, universal across iwi but have whānau, hapū or iwi specific detail. Employing a pūrākau approach enables the diversity to be expressed and also enables the expression of Kaupapa Māori to be viewed within a specific context. Jenny Lee<sup>13</sup> notes that her use of pūrākau was influenced by the explorations of the narrative forms of Indigenous writers, in particular Sarah Lawrence-Lightfoot and her use of the concept of ‘Portraiture’ and Jo-Anne Archibald who utilised traditional story telling traditions in her doctoral research.<sup>14</sup> These Indigenous methods have helped to inspire the use of ‘pūrākau’ as both method and methodology. Māori educationalist Kura Taylor notes that Māori oral literature contained the ideas of the “practices necessary to engage with the

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<sup>11</sup> This is a key theme in the recently released DVD with Senior Māori researchers talking about Kaupapa Māori research. Pihama, L & Daniels, N. 2007 (Directors) *Tikanga Rangahau*, Māori And Indigenous Analysis Ltd., Auckland

<sup>12</sup> Harte, J.M. n/d *Home Births to Hospital Births: Interviews with Māori Women who had their Babies in the 1930s*.

<sup>13</sup> Lee, J. B.J. 2003 *Ngā Tohutohu: A Purākau Approach to Māori Teacher Narratives*, Paper Presentation to TEFANZ Vonference September 2003

<sup>14</sup> Lawrence-Lightfoot, S., Jessica Hoffmann Davis. 1997. *The Art and Science of Portraiture*. San Francisco: Jossey-Bass Publishers; Archibald, J. (1997). *Coyote Learns to Make a Storybasket: The Place of First Nation Stories in Education*. Unpublished PhD, University of British Columbia.

environment in sophisticated ways of the transmission, preservation and perpetuation of valued knowledge were refined through creative, diverse frameworks”.<sup>15</sup> Pūrākau was and continues to be a way of recording our taonga tuku iho<sup>1</sup> and provided the portraiture of our culture. Pūrākau presents us with an appropriate metaphor and a conceptual framework of representation for the experiences that will be recounted and the stories that are to be told. Although pūrākau derives from an oral tradition it may continue to provide the stimulus to write, create and research in ways that are culturally responsive within the present-day context of teaching and learning.

A pūrākau approach enables participants to share their stories from their own context and support the development of narratives for sharing with other whānau and health professionals. A thematic analysis has also been undertaken as a way by which to add the macro level of analysis to that of the micro of the whānau stories.

The research project includes a literature and data review and interviews kanohi ki te kanohi in both a one to one and whānau context. A total of 30 interviews have been undertaken. Participants were recruited through networking with organizations involved in infant or whānau health, and through word of mouth from whānau who were involved in neo-natal units. A series of ten narratives were also developed that will be published online for access by whānau and health professionals.

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<sup>15</sup> Taylor, K., 1994 *Conversations with Māori women educators: Ngā kupu Paake a ngā wāhine Māori*. Unpublished M.Phil, The University of Auckland.:97).

## Literature Review

The beginning of neonatal intensive care, usually credited to Dr. Martin Couney the inventor of the first incubator for newborns, dates back to the late nineteenth century (Gartner & Gartner, 1992). Since then there have been huge technological and medical developments in neonatal intensive care units (NICU) throughout the world, and a dramatic decrease in infant mortality. In turn, an expansive body of research literature about NICU has also emerged, including a focus on the stress of babies (Field, 1994; Anderson et al., 1995; Morelius et al., 2005), stress experienced by their parents (Miles, 1993; Lau, 2001; Holditch-Davis et al., 2003; Pierrehumbert et al., 2003; Shaw et al., 2006), and a wide range of interventions (Harrison, 1993; Ludington-Hoe, 1993; Flossy, 2000; McGrath, 2000; Thomas et al., 2004; Johnson, 2005; Manning, 2006; D'Souza et al, 2009).

According to the Ministry of Health (2005), New Zealand has one of the best survival rates for premature infants in the world. In New Zealand, there are six state-funded NICU<sup>16</sup> in each major city within that geographical region. These NICU are categorized as either Level 3 (high dependency care for extremely premature infants from 24 weeks gestation and sick babies requiring intensive care monitoring and treatment) or Level 2 (babies 32/40 weeks and above and babies who have been transferred from Level 3 units after being clinically stabilized).<sup>17</sup> In 2001, 2.8% of babies in New Zealand were cared for in a NICU. While it is unclear from Ministry of Health reports how many Māori babies entered NICU,<sup>18</sup> Māori women and infants continue to be over represented in statistics related to infant and perinatal mortality<sup>19</sup> (MoH, 2010a), preterm births (MoH, 2010), miscarriages (MoH, 2010) and hospital admissions (Robson, B, Robson, C, Harris & Purdie, 2007). For instance, Māori infant death rates were 64% higher than those of non-Māori, with perinatal conditions (premature birth in particular) one of the major causes of death among Māori infants (Robson and Purdie, 2007).

Despite the plethora of international research literature about NICU, research about NICU in New Zealand is much smaller, and studies focussed on Māori and NICU are scarce. Only one study was located that was directly related to about Māori and NICU (Thompson, 2009). Given the extensive international literature about NICU throughout the world in contrast to the dearth of literature about Māori and NICU, this review is presented in two parts. Part one seeks to indicate the breadth of literature that exists about family experiences of NICU as well as highlight some of the key themes in this literature. In part two, Māori experiences are located in the small body of Indigenous literature related to NICU, and further contextualised within the related Māori health literature.

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<sup>16</sup> The six NICU are located in: National Womens' Hospital; Middlemore Hospital; Waikato Hospital; Wellington Hospital; Christchurch Women's Hospital; and Dunedin Hospital.

<sup>17</sup> Currently there are six Level 3 NICU and three Level 2 NICU.

<sup>18</sup> The MoH reports do not provided admission data to NICU by ethnicity. Furthermore the admission data is not collected by Level of admission, but obtained from DHBs as a neonatal admission.

<sup>19</sup> Along with Pacific, Māori have higher rates of early neonatal deaths, late neonatal deaths, and post neonatal deaths than the total population (Pakeha rates not provided) see MoH, 2010a, p. 3.

## **Part 1: Family experiences of NICU**

Given the seriousness of sick or preterm infants for parents and their families, it is not surprising that a high level of stress is experienced in the fast paced and highly technical environment of NICU. Furthermore, that the stressors associated with being admitted to NICU is a major theme in much of the research literature about infants and their families' experiences of NICU. Factors that contribute to this stress include an operative birth or emergency delivery, premature delivery and the experience of parenting a preterm infant in NICU.

Whereas newborns were originally perceived to have little need for human relationships (Greisen et al, 2009), today it is recognised that newborn babies do experience and express emotional stress, and that this stress can sometimes have long term consequences. For instance, Field (1994) argues that emotional dysregulation in babies can develop from brief or prolonged separations from the mother and her emotional unavailability – often a common experience in NICU when babies are incubated for long periods of time. Field (ibid) found that an infants separation from the mother affected infants play behaviors and sleep patterns. Being physically and/or emotionally deprived of the mother impacts on the emotion regulation or organized behavioral and physiological rhythms of the infant. Emotional unavailability, such as a mother's depression, had the most negative emotional affects on infants.

Similarly, in another study, Anderson et al. (1995) used randomised clinical trials to compare self-regulatory (SR) mothering to Nursery Routine (NR) to look at stress in babies. SR mothers responded to early infant cues, babies lay almost continuously on their mother's chests, sometimes skin-to-skin, and had SR feedings. In contrast, NR babies were usually in a nursery, separated from their mothers. Although this study focussed on 224 mothers and their full term babies (rather than sick or preterm infants), the findings are pertinent to providing the best care in NICU. The study found that NR infants cried more and had higher salivary cortisol. The authors conclude that these infants experience more stress and the SR care may be more optimal method of postbirth care.

The idea that babies benefit from more time spent in close contact with the mother is not new. In an article that compares infant care patterns of mothers in contemporary hunter-gather societies to mothers in the US, Lozoff and Briteenham (1979) show the change in infant care and maternal involvement over the past two million years. In short, mothers used to provide extensive body contact (child carried) and prolonged breast-feeding. Care was consistently affectionate with immediate nurturant response to the infant crying. These practices stand in contrast to present day practices in the US where infants spend little time in body contact, separate sleeping arrangements and delayed response to crying is recommended.

A study by Morelius et al. (2005) highlights the importance of physical contact between the mother baby. In their article, entitled 'Salivary cortisol and mood and pain profiles during skin-to-skin care for an unselected group of mothers and infants in neonatal intensive care', they investigate Kangaroo or skin-to-skin care (SSC) as a method to reduce the separation-dependent stress of preterm infants in NICU. This study included 17 mother-infant pairs at their first and fourth skin-to-skin care. In brief, the mother's salivary cortisol, heart rate, mood scale and stress were measured,



and the infants salivary cortisol and heart rate were analysed. Overall the study found that SSC decreased the mother and infants stress. The authors suggest that the SSC is valuable in neonatal intensive care, mothers need support during their first SSC session, and preterm infants favour the need for individualised care.

While the above study and other research (Ludington-Hoe et al., 1996; Bauer et al., 1997; Richardson, 1997; Fohe et al., 2000) has established that kangaroo holding promotes maternal-infant attachment, builds confidence, improves breastfeeding success and may reduce stress for both the mother and infant, a study by Johnson (2005) examines the long-term benefits of Kangaroo holding beyond NICU. Johnson (ibid) identifies the origins of Kangaroo holding as beginning in Bogota, Columbia (and then in South Africa and Zimbabwe) in the early 1900s as an intervention to maintain infant body temperature when incubators were not available. As a human touch intervention, Kangaroo holding promotes connectedness, decreases anxiety and promotes active parenting. Johnson (ibid) argues that Kangaroo-held infants display less negative emotions, engage in interaction more frequently, and demonstrate improved sleep-wake cycles. In addition, kangaroo care promotes success with breastfeeding and assists in improving the mother's milk supply. Breastfed premature babies are often able to coordinate sucking, swallowing and breath sequence better because they have more control of the milk flow (Ludington-Hoe, 1993).

While the reduction of stress caused to babies in NICU is carefully considered in much of the literature, there is also a large body of research that focuses on identifying and addressing the stressors of parents brought about by their babies being in NICU. A New Zealand study conducted by Roslind Lau (2001) focussed on stress experienced by parents of babies born from 30-35 weeks gestation who were admitted to a special care nursery (SCN). Approximately 60 parents of premature babies and the same number of parents of full-term babies (between 37 and 42 weeks) were involved in this longitudinal (PhD) study. Self-reports as well as 'biochemical markers' of stress were conducted five times during a 24 week period for parents with premature babies, and 17 weeks for parents of full-term babies. In short, the study found that parents of premature babies experienced higher levels of stress largely due to the appearance and behaviour of the babies in SCN, and the delay in their ability to perform a parenting role.

Like Lau's (ibid.) doctoral research, many studies have identified parents of premature infants as being at higher risk of high levels of stress (Miles et al., 1993; Holditch-Davis et al., 2003; Pierrehumbert, Nicole, & Muller-Nix, 2003). For instance, post-traumatic stress disorder (PTSD), more usually associated with extreme or traumatic events such as combat, rape or other disasters, has been identified as a significant risk factor for parents of babies in NICU. Bellini (2009) cites parent-infant attachment issues, depression and perceived lack of partner support as possible PTSD symptoms for parents of NICU babies. In light of this, Bellini (ibid.) encourages nurses (as the frontline staff of NICU), as well as midwives and obstetricians to be more empathetic in their approach to parents by providing active listening, emotional support and debriefing after a traumatic birth.

Similarly, a study by Shaw et al. (2006) documents Acute Stress Disorder (ASD), a form of traumatic stress that occurs in the first weeks after a traumatic event, in parents of NICU infants. This study involved 40 only English speaking parents of

babies in NICU in the United States - 24 parents from couples in which both fathers and mothers participated, 13 mothers, and three fathers. All parents completed self-report questionnaires two to four weeks after the NICU hospitalization of their infants. The authors note that, in general, these parents were well-educated (only 5.6% of women did not have a degree) and of high socio-economic status (large majority family income was more than \$80,000US). In this study, several measures of stress were used:

*Stanford Acute Stress Reaction Questionnaire (SASRQ)* – a 30 item self-report questionnaire to assess ASD

*The Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU)* – a 46-item instrument that included three subscales assessing specific sources of stress

*The Neonatal Index of Parental Satisfaction (NIPS)* – 27 item self-report questionnaire, assessed parents' satisfaction with the medical care of their infants in the NICU

*The Family Environment Scale (FES)* - a 90 item True/False self-report questionnaire that assessed parents' perceptions of their current family environment.

*The Weinberger Adjustment Inventory (WAI)* – a 84 item questionnaire that assessed the dimensions of distress, restraint, denial of distress, and repressive defensiveness.

The key findings of this study showed that eleven respondents (28%) met all symptom criteria used to diagnosis ASD for the stress of having an infant hospitalized in the NICU; 44% of mothers were classified as meeting the symptom criteria for ASD. Greater ASD symptom severity was strongly related to concerns regarding Parental Role Alteration including not being able to help, hold, or care for the infant, protect the infant from pain, or share the infant with other family members — this was the factor most strongly associated with symptoms of ASD.<sup>20</sup> Shaw et al. (2006) suggest that interventions should focus on “reducing the parental feelings of helplessness and inadequacy by establishing the parental role, even with severely ill infants” (ibid.:211). Alteration in the expected parental role is a key contributing factor of parental stress.

While Shaw et al. (2006) found a significant proportion of mothers suffered ASD symptoms, none of the fathers did. Among the 12 couples, the husbands' severity of ASD was not significantly correlated with that of the wife. Increased levels of stress amongst mothers were attributed to their greater psychological involvement with their baby. According to this study fathers were more likely to “discount the severity of the problem, minimize their own emotional response, and spend more energy supporting their spouses during the NICU hospitalization” (p. 209). This is not to say that fathers do not experience stress, rather the stress they experience is sometimes different.

Far fewer studies focuses on fathers' experiences of NICU, one such research study has been conducted by Arockiasamy et al (2008). Aimed at understanding the experiences of fathers of very ill neonates in Canada, sixteen fathers (whose children had been in the NICU for more than 30 days) were included in this study. These

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<sup>20</sup> ASD symptoms were not found to be related to any of the characteristics that directly pertained to the infant's medical status, including length of stay in the NICU, birth weight, gestational age, and Apgar scores.

fathers were interviewed by a male physician and asked about their level of comfort with or concerns about staff communication regarding their baby, about accessing information, and general perceptions of their neonatal intensive care unit. This study found that the overarching theme for fathers was a sense of lack of control. Four interrelated sub themes were: information (obtaining information about their baby); communication (consistency in receiving information); fathers' various roles (taking on unexpected roles and redefining their role in their family structure); and external activities (ie. working, exercising, religious community activities were helpful). Relationships with friends, family and health care team, receiving information consistently, and receiving short written materials on common conditions were ways of providing support. Where the literature related to fathers is limited, it is clear that research within NICU remains focused on the construct of the two parent heterosexual nuclear family structure.

In contrast to the early days of NICU in which the general approach focussed on hygiene and the control of infection, today caring for the family is considered an important part of providing optimal conditions for the care of newborn in NICU. It is evident from the literature that a family-centred neonatal care approach – an approach that advocates that families participate fully as possible in caring for and making decisions for their children – reaps benefits for the babies, their parents and families.<sup>21</sup> According to a study conducted in five NICU in the United States by Riper (2001), when mothers experiences positive family-centered relationships with providers, in particular the nurses, they were more satisfied with the care received and they reported higher levels of psychologic well-being.

Despite the importance of family to the wellbeing of the hospitalised infant and their family, policies regarding family visiting NICU is not uniform. In a study conducted by Greisen et al. (2009) about family access to NICU in eight European countries shows that while policies towards family visiting has improved over the last decade, there is a variance in policies. Greisen et al. (2009) argues that despite research that demonstrates the faithfulness of parents in visiting children as much as possible, and the benefits of unrestricted visiting by family and friends of children in hospitals, there are a range of barriers to unrestricted parental presence in NICU. The study reported that parents are allowed access at any time in all NICU in Sweden, Denmark and the UK (like New Zealand), 90% access in Netherlands and Belgium, 71% in France, and 30% in the Italy and Spain.

In the effort to achieve a family-centred approach to care in NICU, nurses are acknowledged for the vital role they play as frontline staff (Griffin et al., 1998; McGrath, 2000; Manning, 2006; D' Souza et al., 2009). Nurses are usually the main source of information and facilitate appropriate services; moreover, nurses are identified as key in relieving stress for the babies, their parents and families. In a study that investigated the relationship between stress, coping and nursing support of

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<sup>21</sup> 'The principles for family-centred neonatal care' were originally written by a small group of American parents, all of whom had children in NICU. The principles were then further developed at a conference that included physicians led by Dr Lucey (Editor of Pediatrics). Since then the principles have been refined from the suggestions of other parents and professionals intent of seeking how best to provide family-centred neonatal care.

parents of preterm infants, D' Souza et al. (2009) found that nursing support was an essential variant in reducing stress for parents.

Manning (2006) acknowledges the critical role of nurses in involving the families in the care of their babies in NICU in New Zealand. Establishment of trusting relationships, according to Manning (ibid), is key to therapeutic intervention for nurses working with families of hospitalised children. Nurses are encouraged to not only 'care for' but 'care about' – an attitude of concern and commitment that requires a reflective approach of their actions, motives and reactions as nurses. Manning, a clinical co-ordinator in NICU, writes:

*A family is more trusting when they feel the nurse connects with them. They feel accepted as people and perceive the nurse as a fellow human being – the child is recognised as a person, not just a patient or a diagnosis; the nurse shows concern about the well-being of the infant and family; the child is treated with dignity and called by his/her correct name; there is recognition of the parental role; and there is continuity of care (ibid.:19).*

Manning points to the guarded alliance (GA) model, a three-stage development of trust originally developed with families of chronically ill patients, and the family-centred care (FCC) model as important basis to understand the nature of the care required in NICU.

The literature about experiences of NICU is extensive and often complex as every aspect of the NICU experience is explored from the admission and/or transportation to NICU (Morrone, 2008), ethical issues affecting babies and their parents in NICU (Nuffield Council on Bioethics, 2007), to the follow-up care babies and families receive in their homes (Henry, 2008). The intention here is to highlight some of the key themes in the literature related to family experiences. Firstly, it is evident that having a infant admitted to NICU is often overwhelming. The NICU environment, filled with medical and technical equipment, is foreign and restrictive to most families. Moreover, the inability to participate fully in parenting and relinquish much of the control to health professionals creates anxiety and a high amount of stress for babies, parents, caregivers and families. Secondly, the effort of nurses and other staff to practise a family-centred approach that also encourages interventions such as kangaroo care and breastfeeding can help mothers and families cope and feel supported.

## **Part 2: Indigenous and Māori experiences of NICU**

While it is difficult to locate research that had focussed on Indigenous peoples experiences of NICU, it is apparent that there are many commonalities associated with neonatal births amongst Indigenous women. Indigenous women experience poorer birth outcomes high infant mortality (Sayers, 2009), higher rates of low-birth weight and pre-term births (Alexander et al, 1998; Cass, 2004; Thompson, 2009; Sayers, 2009).

An Australian study that examined whether very premature infants born to mothers residing in rural areas have poorer outcomes than those residing in urban areas in New South Wales, found that rural mothers were more likely to be teenaged, Indigenous, and to have had a previous premature birth, prolonged ruptured membrane, and antenatal corticosteroid (Abdel-Latif et al., 2006). Despite the fact that the majority (83%) of NICU rural babies included in this study were born in tertiary centres, rural inborn infants had a higher mortality than their metropolitan counterpart.

In the United States, Baldwin et al. (2002) found high rates of inadequate pattern of prenatal care and of post-neonatal infant death Native American and Native Alaskan mothers compared with White women regardless whether they resided in rural or urban areas. The rates of receipt of an inadequate pattern of prenatal care were more than twice the rates of Whites during the same time period. Similarly, low birth rates and neo-natal death rates were much higher than White women.

Sayers' (2009) study of newborn care of Indigenous people of Australia, Canada, the United States and New Zealand recognises that each of these groups have lower incomes, poorer education outcomes, poorer food security, lower home ownership, and limited access to health services as compared to the non-Indigenous populations in their respective countries. With regards to newborns, a higher infant mortality rates compared with the non-Indigenous populations is also a commonality shared between these Indigenous peoples. According to Sayers, Aboriginal peoples experience the greatest disparities with infant mortality rates three times those of the non-Indigenous population, as well as the higher rates of (neonatal mortality (deaths per live births up to 28 completed days after birth) and post-neonatal mortality (deaths between 29 days and 364 days after birth)). Sayers discusses low birth weight, fetal growth restriction, preterm birth, large for gestational age and macrosomia (birthweight >4.5 kg or >4 kg), as well as smoking, alcohol consumption, obesity, diabetes, Maternal undernutrition and stress, and teenage pregnancies as some of the factors associated with neonatal mortality rates for Indigenous peoples.

In Australia, Canada, and New Zealand, indigenous postneonatal mortality is higher than neonatal mortality, a pattern consistent with disadvantaged populations and usually related to conditions associated with high-risk births (low birth weight and preterm births) and congenital abnormalities. Teenage pregnancy (maternal age <19 years) is a risk factor for preterm delivery as well as low birth weight.

New Zealand statistics confirm that Māori follow the pattern of poor maternity outcomes and newborn care of other Indigenous peoples. The MoH report 'Hospital-based maternity events 2006' (MoH, 2010) showed Māori women over represented in the most deprived socio-economic deciles, they have a younger age structure as mothers, and higher birth rates than the national average. In 2006, the median age for mothers was 30.3 years old. Māori mothers were more likely to be younger (20-24 yrs), and more likely than any other ethnic group to be a teenage mother (ibid:10). Māori also had one of the highest rate of miscarriages<sup>22</sup> (ibid.:20) and preterm births (born less than 37 weeks' gestation) (ibid.: 42). Of babies born prematurely, Māori babies had the shortest length of stay (up to 2 days) compared to Pākehā babies who stayed on average between 2-6 days (ibid.:53).

The latest edition 'Hauora: Māori Standards of Health IV' provides more Māori health statistics from the period 2000 to 2005 within the broader context of health in New Zealand. In relation to Māori hospitalization, from 2000 to 2005, Robson et al. (2007) found that pregnancy and childbirth was the most common cause of admission among Māori.<sup>23</sup> For Māori infants, the major causes of hospital admission (apart from healthy live births) were perinatal conditions and respiratory disease. Yet, Māori babies had only around 60% the non-Māori rate of admissions for perinatal conditions, including lower rates of admission for premature birth. In an overview of Māori mortality, Robson and Purdie (2007) report that Māori infant death rates were 64% higher than those of non-Māori. Perinatal conditions (premature birth in particular) and sudden infant death syndrome (SIDS) were major causes of death among Māori infants. (ibid.:34).

According to Reid and Robson (2007) these inequalities in health, better described as 'health inequities' should be understood in relation to our colonial history but how resources, including health services, are distributed to the community. These two factors are inextricably connected, they write:

*In essence, colonisation permits the (mis)appropriation and transfer of power and resources from indigenous peoples to the newcomers. This process of transfer is enabled by layer upon layer of new systems established to determine how resources will be obtained and how they are to be redistributed and to whom. These systems, therefore, construct who will benefit and be privileged (ibid.: 5).*

In turn, unequal health outcomes can be viewed as a result of environmental factors that impact on health and shape inequalities between groups, such as, racism. As well as institutionalised racism (differential access to the goods, services, and opportunities), interpersonal racism (prejudice and discrimination), internalised racism (acceptance by stigmatised groups of low ability and worth). Jones (2001 cit. in Reid and Robson, 2007) frames racism in relation to health inequities in the following ways:

Differential access to the determinants of health or exposures leading to differences in disease incidence.

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<sup>22</sup> Pacific women had the highest hospital miscarriage rate (6.6% per 100 mothers). Maori women miscarriage rate (6% per 100 mothers).

<sup>23</sup> This excludes admissions for specific procedures and healthy newborns (factors influencing health status not associated with illness, injury or childbirth) (p. 63). The second most common cause of admission amongst Māori was injuries and respiratory disease.

Differential access to health care.  
Differences in the quality of care received.

Reid and Robson (2007) use this framework to draw attention to the ways Māori experience these aspects of racism. Furthermore, they argue racism is a major determinant of health and fundamental driver of ethnic inequalities that must be addressed in order to improve Māori health outcomes and reduce inequalities.

A study that provides an example of 'differences in the quality of care showed Māori receive poorer care than Pākehā in state-funded hospitals. This research was a retrospective cross-sectional study of 6579 patients admitted in 1998 to 13 hospitals (with more than 100 beds) conducted by Davis et al. (2006). The study found that 14% of Māori hospital admissions were associated with health care mistakes. Davis et al. write,

*Māori patients in 1998 had a higher risk of preventable adverse events in hospital than did patients of non-Māori/non-Pacific origin, suggesting that Māori were more likely to receive suboptimum care. (ibid.:1923).*

In order to address such disparities, the authors suggest utilising a framework proposed by the Institute of Medicine which suggests four broad categories: legal, regulatory and policy matters; health-system issues; empowerments of patients; and cross-cultural training (ibid.:1924). It follows, as other studies show, that when Māori are poorly treated by a health service they are less likely to access the service again (Cram et al., 2003).

While there are a growing number of research articles about the barriers to accessing health care for Māori, as Bolitho and Huntington (2006) point out there is very little qualitative research on Māori experiences of health care. Hence, their study 'Experiences of Māori families accessing health care for their unwell children: A pilot study' (Bolitho and Huntington, 2006) seeks to contribute to this literature by providing insights qualitative data can offer. This study included four Māori families which children had stayed in hospital (for a minimum of one night) with their children and had been admitted for a respiratory condition. Included in the key findings, the study showed that while statistics reveal that Māori are more likely to use secondary care services such as emergency departments rather than a primary care provider (Grant et al, 2001), Māori families preferred to access primary care and be seen by their family doctors (rather than go to an accident and emergency department). However, due to the difficulty in accessing their doctor because of work during the day they had to access health services after hours. Bolitho and Huntington (2006) write:

*Māori parents accessed health services for their children as soon as they were able. However, each family's ability was dependent on availability of resources such as transport, conditions of employment and money. These conditions impinged on how they were able to access appropriate health services (ibid.:31).*

Māori families also described feeling vulnerable in health service, their knowledge of their children often overlooked or dismissed because they were not the health professional, and there was a tendency to minimise the severity of the illness of their child.

Another qualitative study related to the topic of Māori whānau experiences of NICU, is a PhD study conducted by Denise Wilson (2008) of Māori women's experiences of 'mainstream' health services. In this research project she interviewed 38 Māori women aged between 24 and 61 years old. Wilson highlighted the findings of the 2006/7 NZ Health Survey that showed Māori women had the highest level of unmet need by GP services, were less likely to have been seen by a medical specialist in the previous 12 months, and more likely to have an uncollected prescription. Māori women also reported that health professionals were less likely to treat them with dignity and respect, listen to what they have to say, and discuss their health care adequately 'at all times'. In addition Māori women also experienced higher prevalence of high or very high probability of an anxiety or depressive disorder. From the interviews conducted in Wilson's study she identified four broad dimensions important for Māori women and their health: connecting through whānau; nurturing wairua; using matauranga; and undertaking self-care activities. Similarly, Palmer (2002) points out that literature about Māori maternity consistently highlights the importance of: cultural safety, whānau oriented services and access to Te Ao Māori childbirth resources.<sup>24</sup>

As stated from the outset, to our knowledge only one study specifically about Māori whānau experiences of NICU has been undertaken. Keri Thompson's (2009) MSocSc thesis, entitled 'Māori whānau experiences of neonatal intensive care unit: Waikato Hospital' featured a narrative inquiry of six whānau stories. The mothers in this study are aged between 17 to 37 years old, and affiliate to variety of tribal groups. Apart from two whānau who reside in Hamilton, the other whānau live in the wider rural Waikato region. As Thompson (ibid.) points out, each of the six korero forms a unique case study, there was no uniformity in whānau circumstances, medical conditions and nor their experiences. Despite the diversity of experiences, Thompson provides a useful analysis that draws on some of the commonalities of experience and key themes that are grouped under the following headings: birthing experiences; transition through the NICU, and; relationships in the NICU. A brief summary of these themes follows.

Under the heading 'birthing experiences' the antenatal care the women was discussed. The two teenage mothers in this study, were unaware they were pregnant till late in the pregnancy (one realised when she began having contractions) and therefore did not receive adequate antenatal care and experienced high levels of stress. As a result they felt completely unprepared for entering NICU. In contrast, Thompson found the women who received antenatal care were able to prepare a birthing plan and better cope with NICU. As part of the birthing, two of the six mothers discussed incorporating specific cultural practices such as karakia. While one whānau was able to conduct their birth in the way that they has planned with their midwife, the cultural practices of the other whānau were ignored and interrupted by midwife resulting in distress and negativity amongst the whānau. Thompson concludes,

*Māori mothers young and old, and their whānau, are more likely to feel in control and empowered when there is positive communication and inclusion in*

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<sup>24</sup> See: Bryant, 1994; Ellis, 1998; Harris, 1994; Ministry of Health, 2001; National Health Committee, 1999a, 1999b; Ratima, Durie & Potaka, 1994.



*the birthing process, regardless of any medical interventions that may occur. (ibid.:86).*

Due to variety of reasons, only some of the mothers were able to have whānau in attendance at the birth of their babies. The mothers whose whānau were present referred to an emotional, cultural and spiritual connectedness during birthing, in contrast those without whānau felt a sense of 'loss'.

In relation to 'transition through the NICU', like other mothers in the research literature, Māori mothers in this study also felt overwhelmed and disorientated. For the mothers who lived outside of Hamilton, the initial separation from their babies was exasperated by their separation from their whānau. One mother refused to visit her baby until her whānau arrived, she said

*I wanted to wait for them to be there too ... um it was an experience for all the children because they didn't know why I couldn't take their brother home (ibid.:54).*

Mothers also experienced difficulties when they were unable to touch and breastfeed their babies due to the incubators and technical equipment. Thompson (ibid.) points out, however, that the practice of kangaroo care and the opportunities to care for babies 'skin to skin' was an important part of bonding and parenting for all the whānau.

The narratives collected by Thompson show that while whānau felt confident about the medical expertise and technological care their children received, the relationships that were formed with staff and others had a huge impact on how they felt at NICU. Under the heading 'relationships in the NICU' Thompson discussed the importance of relationships to the whānau experiences of NICU. The relationship between mothers and the nurses was an important one for Māori whānau. One whānau felt they were treated like 'naughty school children' (ibid.:91), and two other whānau felt frustrated and powerless by the treatment of the nursing staff. On the other hand, when nurses assisted the mothers and their whānau with explanations, praise and care whānau gained a sense of confidence and were able to shift from passive observers in NICU to more of an active parenting role. Whānau responded positively to being provided with more information and responsibility to care for their babies. Of all the relationships, Thompson reports that all the participants identified the importance of being with whānau. She contends that whānau support was considered to be the most valuable source of support for mothers in an NICU. A poor understanding of whānau by NICU staff detracted from providing appropriate support. Thompson writes,

*Whānau support was compromised when understanding of the whānau by the NICU practitioners differed to the needs of the mothers (ibid.:100).*

When whānau were unable to actively support, mothers found that support from others such as parents who had similar experiences, were helpful in lessening the stresses of being away from their whānau.

Given some of the issues raised in Thompson's study related to a lack of cultural understanding there appears to be a disjuncture between practice and policy. There are various New Zealand frameworks aimed at promoting wellness, including Māori well-being, that have been officially accepted and implemented. These include; the

NZ Health Strategy (King, 2000); the Primary Health Care Strategy (King, 2001); He Korowai Oranga (King & Turia, 2002); Child Health Strategy (MOH, 1998). For instance, He Korowai Oranga promotes whānau as the source of identity, security, support, and strength for health care. The strategy asks for health workers to consider individual patients as part of a whānau, and to take a multidisciplinary approach and collaborate with housing agencies, social service providers, and other specialists to support the wellbeing of the whānau.

There are also various Māori frameworks that provide guidance for health professionals, educators and administrators to promote Māori health. These include: Te whare tapa wha (Durie, 1994); cultural safety (Ramsden, 2002); Te wheke (Pere, 1991); and Hōmai te Waiora ki Ahau (Palmer, 2002). These Māori models are important because, as Palmer (2002) points out, conventional well-being measures:

*Are not responsive to the needs of Māori.*

*Are not based on Māori concepts or constructs.*

*Do not facilitate Māori participation in te ao Māori.*

*Do not provide pathways through which Māori can develop a positive Māori identity (p. 87).*

Māori models respond to the needs of Māori, furthermore they highlight the need for a reorientation of health services. Durie (2003) suggests two pathways to improve services and outcomes for Māori: increase the responsiveness of conventional services, and; establish dedicated Māori health programmes. In relation to a 'mainstream' health service like NICU, Durie (ibid.) suggests:

*Improved responsiveness requires health services to recognise the significance of culture to health and to adopt methods that actively engage patients—through appropriate language, respect for custom, the use of culturally validated assessment protocols and outcome measures, and the employment of indigenous health workers (no page number).*

Durie (ibid), Reid & Robson (2007), Palmer (2003) and others also remind health professionals that the motivation for better servicing the needs of Māori is not only about reducing disparities between Māori and non-Māori. Rather the Treaty of Waitangi, recognised in section 8 of the New Zealand Health and Disability Act (2000), requires health inequities to be addressed and health gains made for Māori.

## **Summary**

Within the expansive literature about NICU, there are few studies about Indigenous peoples, and only one that specifically addresses Māori whānau experiences of NICU. Yet, statistical data shows Māori experience poorer birth outcomes (like other Indigenous peoples) than non-Māori in New Zealand, signified by higher rates of miscarriages, preterm births and perinatal deaths. Coupled with literature about health inequities, it is important that Māori maternity and birth outcome data should be understood in the context of a history of colonisation and through determinants such as racism. This review draws attention the need for such studies and the present gap in the NICU literature.

Keri Thompson's (2009) sole study of Māori whānau experiences of NICU shows that aligned with the themes identified in the wider NICU literature, Māori also experienced high levels of stress during their time at NICU that was, at times, mediated by NICU staff (in particular, nurses). However, the six whānau narratives included in Thompson's study serve to highlight the ways 'being Māori' is an important dimension to understanding their experiences of NICU, in particular, the importance and inclusion of whānau in NICU. While Māori whānau appreciated the life saving technology and medical expertise accorded to their babies, their ability to maintain their cultural identity and practises was an important factor in describing their experiences of NICU. This aspect of Thompson's study resonates with wider Māori health literature that recognises the salience of culture. Furthermore it reinforces calls for health services to be more responsive to Māori needs, not only to reduce disparities between Māori and Pākehā, but to fulfil the government's responsibility to the Treaty of Waitangi.

## Ngā Pūrākau: Whānau Narratives

As a part of the project a series of narratives were developed from the interview material from whānau. This section includes ten of those kōrero from whānau who share in their own voices some of their experiences in NICU. For reasons of confidentiality each narrative is titled by the first initial only of the whānau member.

### M.

I had just had baby and she was three months old when I found out I was pregnant. I hemorrhaged and he came on. He was 815 grams. We both nearly died many times that night. It took them a week to find me a place to stay, but it was awesome when I ended up learning how to do everything for him. When the nurses weren't there I would try and do everything for him. I sat there everyday.

One of the babies had a flu and the nurse, she forgot to wash her hands and went straight to him boy and it looked to me like he got instant Chicken Pox. It just came up on him and the bells were ringing and we all panicked. He stopped breathing twice. He couldn't breathe on his own and he had chronic lung trouble.

I had to take care of myself. We had to find our own food and at night you weren't allowed visitors in your room. It was very lonely and stressful. I had a problem with a woman there who became a friend, but it turned out she was a social worker. She told her work the issues I'd confided in her as a friend. That was a big shock. So after awhile the mothers there all decided to keep quiet and we just helped one another really as we knew that way that our information was not going anywhere.

I found that the nurses preferred us there especially if you were the mother so to get out was hard. So I said to them 'why don't you go and get some people in get some old ladies in to sit with some of the babies during the day'. I think I started something as they said it was a good idea. They got in an old Islander lady and she was like a Granny, she was wonderful.

We were only allowed one other person there in the unit and mostly it was the father or a relative that came from far away. There was nothing in place for them. They would come and visit and then weren't allowed to sit around with the baby. The positives for me were mostly the care for boy. He was well cared for, you could see that and you could sleep at night after awhile. I think I adjusted to everything pretty fast and my main aim was to stay out of their way. There were other babies wired up so I sat in the corner way out of their way. I learnt and I studied the medicine and the machines they were using and I occupied my mind with learning that. So I would say to mum's and whānau 'you have to look after yourself'. They (the staff) really did just stick to the care of the baby. Most of the nurses I became close with. There was no room for visitors. There was a tiny room and that wasn't enough room for whānau.

My dad had to go and ask the nurse if he could give baby a blessing prayer when he came through. At first they refused and I said 'Dad you can bless him in your mind'. So dad got a bit sore about that. He wanted to leave something with baby, but your not allowed to leave anything in here because of all the wires running and that. We didn't have any Māori support group. There was nobody to talk to other than your nurses. There really wasn't anyone coming around to talk to you, we had to work it out ourselves. I really think they should put some people in those places. Our young

boys and our young girls are there and the stress is too much, they are just not handling it. It's lucky that the other mothers help each other.

## E.

We had our son at Wellington Hospital, he was seven weeks prem. I had gestational diabetes so my blood pressure was high and we didn't want to put pressure on baby. I had a caesarean at 33 weeks. He was four pounds, six ounces. He had neonatal hypoglycemia and his lungs were small but he was okay. He stayed for seven weeks being supported with oxygen and increased glucose through IV. When he started regular eating patterns he gained weight and his glucose count increased. It was a slow and irregular pattern, complicated by infections. But slowly he got stronger and stronger. We weren't in a hurry to leave Neonates because it was a bitter winter and the risk of his immune system not being able to cope was too high.

My diabetes cleared once I'd delivered Josh so I was discharged within a week. We lived up the Kapiti coast and so for the last few weeks that he was in hospital I stayed in a parent room at the back of the unit. That was a big help. My partner and his whānau stayed home and took care of our other kids, while I stayed with baby. If I wasn't able to stay in one of the parent rooms, I would've been pretty stressed out. It's a long way to travel from the coast to Wellington everyday. I was able to cook and sleep at the hospital and my partner and the kids would come in often. Sometimes when he really had to go to work and couldn't watch the kids, they'd come and stay with me at the hospital, we could do that with the parent room, they'd hang out watching DVDs or play in the room anytime I went to do babies cares. We'd go for walks to get a break from the hospital. But most of the time the older kids were with their Dad and Gran.

I saw a lot of Māori whānau come through the unit, some were pretty independent and some needed lots of help, particularly the younger ones. The older whānau, helped the younger whānau too, we'd all have kai and we'd all try and give support and advice, "go see the ward nurse", "go see the support parent worker", "ask your doctor for a letter to show your boss" etc, it was good to help someone where you could, it's about the only thing we could do, we couldn't do any of the medical stuff.

I remember a whānau arrived and you knew their baby was at risk of not surviving. Their baby did die. It was hard for every parent in the unit when that happened. You don't like to hear the waiata and karakia and know what was happening but be a stranger on the outside. One of the other parent's did a karakia whakanoa, for the ward and for those of us still in the ward after the whānau had left. We mostly just did it all ourselves. There was a minister in the hospital who could've done it but we never contacted him, we just did it ourselves. I think that staff need to be aware of these issues of importance for us because while we were confident enough to do it for ourselves, there may not be others who could do that.

We still keep in touch with some of the whānau we met while there. It was a hard time but one that we got through with tautoko from other whānau.

## J.

I had my son ten weeks early, I had pre-eclampsia I think it's called. He was born by emergency caesarean. My sister and aunty were there. His father wasn't around. Baby wasn't breathing when he was born, my midwife was really quiet but when he did cry everyone was relieved! He went to NICU and I had to stay in recovery. My aunty went to the ward with him, my sister stayed with me. Baby had a hard time over the next while.

What was hard for me was not being able to have a "normal" baby, not being able to have him on the ward and not being able to hold him. Nothing about his birth was normal, no whānau able to see him and if they did it could only be for a brief moment. It was isolating not being able to tell or explain what was happening. All anyone knew was I'd had a baby but he was severely premature. Isolation was hard, I had all the whānau and I had all the contact with people but others didn't understand a lot.

We went through weeks of ups and downs, lumbar punctures, blood transfusions, ventilation, operations, tests, tests and more tests. The parent helper at NICU helped a lot with questions, she'd give me books and talk me through procedures and what was happening, she knew a lot of what happened in the ward so she was really supportive. There were a lot of staff to help, something's they helped with were good, others I'd change. Like we wanted to bless boy and we could only do it with a small rōpu so everyone else stood out in the corridor and had karakia. That was a big one for my whānau. They needed boy to be blessed as soon as possible but he was so sick not everyone could come in. In the end the minister and my nan came in, the rest of the whānau waited in the hallway.

I had to stay in hospital for a while to bring my heart rate down but that worked for me too, it meant I could stay near to baby. The hospital became our nursery. And the best thing was, the nurses taught me how to care for boy. Only the other parents in the ward know what you're going through. Mates and whānau would know a little bit but the hard and good times are shared among those who are there in the ward, doing the hard slog. Like when he wouldn't keep down food and lost weight, I stressed a bit about that and another parent explained the more I stressed the more he stressed. So I had to chill out.

If there's anything I'd improve it would be accommodation for whānau, I was okay because I was on the ward but I saw a few whānau struggle with accommodation. Particularly when Ronald McDonald House was full. And accommodation for extended whānau not just mum or dad. Sometimes on a weekend you might just need some space for whānau. I don't even know if Wellington Hospital has a whānau room. And maybe a go between for you and doctors so that someone can explain what's happening to you and your baby and why it needs to happen or why it doesn't need to happen. Having an advocate for you. So that's what I'd improve.

## L.

I have endometriosis so conceiving was hard, I had IVF treatment, it took a long time so when my pregnancy test said positive I was a bit shocked. I was even more shocked when the scan said I was having twins. The pregnancy was difficult, we were always in the midwife's office for check ups. At 33 weeks my midwife said she wanted me to go to hospital for another scan. The scan showed the babies heart rates were low. So I went to hospital and the next day the obstetrician and I agreed that we needed to have the babies. The babies were locked so I couldn't have a natural birth. The babies were born that afternoon by caesarean. Seven weeks early. They were fraternal boys, well formed but very low birth weights, two pounds five and almost four pounds respectively. It seemed that one of the babies was getting nutrients in the womb and the other wasn't. There wasn't anything medically wrong with the boys, they were just "under-cooked".

I had good and bad experiences in NICU. The biggest issue I had was I didn't feel the doctors would explain what was going on enough. I didn't enjoy doctors rounds. The doctors seemed to talk among themselves and not to me and when they did talk to me it seemed simplistic.

The boys weren't as sick as other babies so there weren't any big complications with them but the doctors still wanted to order a lot of tests and scans that I wasn't sure I wanted to have done. There was also a trial that if your child was a part of you got a gold star on the chart. I didn't want my babies as part of the trial so I wouldn't sign consent. No gold star for us.

One of the good things about NICU we had was the nurses support. My partner worked odd hours but he was able to come and go to the ward as he needed. Sometimes the nurses would get him a lazy boy chair and he'd have a nap there. He didn't do that often but it did happen twice when he'd worked long hours and was on call. I traveled back and forth from home. We lived local so travel wasn't hard but it was hard leaving the boys in hospital.

I was too tired to stay in the ward all day and night. I had to go home and rest or I'd be too run down. That wasn't easy leaving the boys behind, we asked the hospital if we could set up a roster of whānau and friends to help care for the boys. That took a bit of negotiation, the hospital seemed to have a fixed rule of only parents to visit babies but eventually we talked them around.

My sister in law would bring in milk in the mornings and my mum would do it at night. I'd come in mid-morning and do cares and then my partner would come in the afternoons to see them and have kangaroo cuddles. It's a routine we got into for the six or so weeks they were there and it was a big help on us. I can't stress how hard it was leaving the boys there but having my whānau with them made it possible. When the boys gained weight five pounds and six and a half pounds they were discharged and we came home.

## M. & D.

Baby was born ten weeks early. My heart rate fell so I had an emergency caesarean. We still don't know why I got so sick, the pregnancy up until then was normal. He was just over a pound when he was born and really sick. They had to resuscitate him at birth and he spent the next two and a half months in NICU. I had a hard time in NICU, I questioned everything they did. In the end I asked my GP to mediate with the staff and I.

I also didn't want to do all the tests and trials they wanted. Especially the research trials. So I wouldn't give permission. It was a hoha having to opt out instead of the other way around of giving consent. I dread to think how many others didn't know they'd automatically given consent.

I had a couple of meetings with the ward director about my issues. Sometimes we'd reach a resolution, other times we'd disagree. I remember saying to her one day, there's a lot of young kids here that need help especially with money, she said that's what the social workers were for, I said you need Māori social workers because these kids aren't responding to the ones you have. She said she'd contact the Māori whānau workers but we never saw any of them.

I had a mate who was a doctor at the hospital and she'd tell me about the medical terms and what they meant, if there was one of those, a Māori one of those I think that'd help whānau Māori a lot more. Everything else in NICU was good, I mean the medical help they give is world class. It was just the clash of how we wanted things done and how they did things where we had problems and we didn't really resolve them, we kind of took things day by day but it made for a long ten weeks.

We didn't like NICU so we had to do rosters. We worked it so one would do the days and the other would go in for nights. It wasn't an easy place. The staff tried but we had to explain a few times how we'd like things done, we really wanted them to say something to him like 'kia ora' before they touched him but that seemed pretty hard for them to do. We'd would have a go at them for touching him with at least saying what they'd be doing first.

We've had two kids since baby and thankfully we haven't had to go back to NICU. Not because it wasn't good for him because it was the best place for him, it just wasn't fun for us.

The stresses were enormous on both of us. Too stressful to do it again.



## N.

I had sharp pains when I was 30 weeks pregnant, I went to A&E, they did a scan and said there was low fluid in the uterus. I was admitted to hospital and monitored. I spent three days on bed rest until the obstetrician said they needed to remove baby as baby would get stressed. I agreed straight away, I could feel something wasn't right with baby. I couldn't be induced, or have a natural birth, the doctor thought that it would be best just to take baby out rather than stress her and I, so I was prepped to have a caesarean. I rang my whānau and they came straight away. Baby was born within hours. She was 2lbs 9oz. Baby's birth wasn't easy, she wasn't lying the right way and it took a bit of pulling to remove her. But she came out and was taken to NICU. Baby had small lungs and her spine and leg were affected by her difficult birth.

We spent nine weeks in NICU. I was still a patient so I was able to go from my ward to NICU. The staff on the woman's ward and NICU were nice, they let me stay in NICU as much as I could, showed me how to express and freeze the breast milk. Baby was only taking a couple of milliliters of milk then. Baby's problem was her early birth, she wasn't strong enough to leave hospital so we stayed until her full term. I had a Pākehā social worker, she helped me sort out my benefit and get a grant to help with clothing for pepi and I. She also helped me with Plunket to get a car seat.

The hard part was trying to understand what was happening and understand the doctors. The nurses explained as much as they could about what was going on. Also there was a support parent person in the NICU unit. She made lunches for parents and there was a parent group that met all the time. She was lovely.

I met a lot of other whānau through this group so when we were on the ward we were able to talk a lot more. My daughter needed a blood transfusion a few weeks after she was born, at the time I didn't understand why but I was so stressed I said yes. Baby improved after that.

I have a big whānau and trying to keep them from swamping the ward was hard sometimes. One day we were able to move baby into an unused room and the whānau were all able to see her at once, that helped them understand that the ward had lots of sick babies and they couldn't come and go as they wanted. I think seeing all the machinery and the incubator and all the equipment freaked them out a bit so they didn't get angry when they couldn't see her.

I don't have a partner but I didn't do it on my own, my sister and best friends were there all the time, they'd just catch a bus and sit with me because parking at the hospital was a nightmare. They'd bring food and whatever else we needed. We went home after about ten weeks. Baby is a small child and has ongoing breathing issues but she's happy and healthy and we're thankful.

## R.

We had problems having babies, my partner would get hapū and the baby would miscarry. This happened over eight or nine years. We made it to 22 weeks one time I think and we thought this time we might be ok because usually we lost baby at six or nine weeks, early on anyway but no, that baby stopped moving and the scan showed it had died. She had to carry a stillborn pepi for a while after too, we waited for baby to pass naturally but in the end the doctors induced the baby. That was the hardest for us. We both took it hard, her especially. We don't know why the babies died. But we were pretty down after that. We decided to stop trying for more babies. It was a sad day when we realised that we didn't think we'd ever have kids.

Blow me down 18 months after the stillbirth we got pregnant, we didn't tell anyone, no one knew except us in the first three months, we didn't tell anyone until she started to get a puku around five months. This was the longest we'd ever carried a baby and I was keen.

One day I was asleep and she woke me up and said she was bleeding. I took her to A&E and they said baby's heart rate was slow, the doctor said he thought it was best for us to have baby. We knew we had nothing to lose and everything to gain so we agreed. We went to theatre and the doctor delivered baby. I was there, I got to hold her for a brief second. They told me it was urgent to get baby to the unit, I saw how small and weak she was so I didn't argue. I'm a farm hand and we probably wouldn't keep stock that sick and small. We all ended up in the helicopter and then into the unit. She went to the post-natal ward and I stayed with baby.

I crashed on the couch of a mate's place and went back and forth to the hospital. I had to go home to cover the farm and work and take care of everything there, so her mum came. Her mum came down and took her home. We agreed that was the best for her, but I got the feeling that the staff thought she was abandoning our baby and that I was domineering. I remember telling the staff that we had talked and that we thought it was best for her to go for a break and the nurse said to me she thought she should talk to her doctor. I managed to talk to a couple of people who finally understood and they talked to doctors and so on. I reckon though if I wasn't older, I could've been ignored by doctors and nurses.

That's the biggest problem I found with our time in neonates. It was so busy that family wellbeing was forgotten and the only concern was baby's wellbeing. That's the priority of course but a whānau is everyone not just one person.

W.

My ex-girlfriend had our son early, nine weeks early. He was due in July but she had him at the end of May. She was bleeding one day, we thought she was miscarrying so we went to the hospital. They couldn't stop the bleeding, it wasn't a lot of blood but they said it was best to have him. So, she had a caesarean. I was there when he was born, he was really small, he was three pounds eight ounces. They wanted to take him to the baby unit in Wellington so they flew my ex-girlfriend and our baby by helicopter. My mum and I drove down. The ex was in the maternity ward and baby was in the baby unit. I stayed in the baby unit with him and mum and I stayed in Ronald McDonald House. We went back and forth from Ronald McDonald House. We don't know why he was born early or why she was bleeding but they were both sick.

My mum helped a lot with the medical things, when they needed to take son for tests or the operation on his heart. He had a heart problem with his valve. Mum mostly talked to the doctors, I mostly talked to son.

I didn't see a lot of other young fathers. It was mostly mums and older people. There was one other Māori fullah in there at the time. He and his missus were taking care of their baby. He and I would have a smoke in the car park and talk. That was good. A social worker came and helped me with the dole. I had to quit my job so I could stay with boy but that was ok I didn't really mind. The ex couldn't express a lot of milk so they had to feed boy with powder plus she was still too sick to come and be with him a lot. It was mostly mum and I.

Mum had to go home after the first week but she'd come down on the weekends. That was good because she'd give me a break. The ex's mother came down a bit too. I didn't really have any whānau in the city. They all came from up the line though. The hospital people helped me, the nurses and that. If I needed anything else I'd ring mum and an Aunty and she'd come in whenever I needed.

There weren't a lot of Māori people in the hospital when we were there. Not workers anyway but I met a lot of people through Ronald McDonald House. Boy was in the baby unit for a good three months. I stayed there. I got the dole, so I was ok to stay there.

The ex was in hospital for a month or so and then we'd take turns being with boy or going back home. After his operation and his valve was repaired we stayed in hospital a bit more but he got better and he was healthy so we came back. I'm boy's primary caregiver now. He's almost six and he's good.

## K.

I fell pregnant at 17. My pregnancy was a bit rough. Somehow, we're not too sure I contracted Hepatitis B, I found out I had jaundice and found out I had Hep B. So I was put in hospital and I pretty much stayed there until I had her. She was three months premature, so I was in there about six weeks prior to having her. I went into premature labour. Luckily we stopped, my liver was already in pretty bad shock. I was 31 weeks. For three weeks they were giving me steroids, prednisone, to help mature her lungs faster.

I had a C-Section I do remember throughout all of that because you can stay awake or not. Well that didn't work for me. They started cutting and I said "I feel that" and they weren't listening, and I'm like "I can feel it," and they were like "you shouldn't." They'd cut me and I could feel it. That's what I remembered I could feel them cutting. Next time I woke up I didn't know where the hell I was, so I passed out and that was it, they just knocked me out after that.

It was a day and a half before I got to see pictures of her. I think because I was out of it. I just remember the first thing I saw was pictures. I was so out of it with the medication and morphine and everything. It was the third day, I remember that we couldn't touch her, that was hard. I watched the nurses do it because she was just hooked on so many machines. She had everything coming out of her. She had little tubes out of her nose and out of her mouth and both her arms were all you know, lures and needles and out of her feet.

Touching her for the first time was frustrating but hard, because when you did touch them they get too much frights. So the less handling is the best for them that's what we got told, at that stage, because her heartbeat would stop. Her sugar levels dropped at several occasions I do I remember that because they rung me in the middle of the night and said "you need to get down here," and I was so afraid of losing her. It was hard not being able to touch. You know you watch someone else touch your baby but we couldn't no matter what. It was awful, that was hard. I did not bond with her for years.

Baby received the best care that she could of. They did amazing things. Like keeping her alive for starters. I'd ask some questions and stuff but I was shy. I didn't know what to do. One thing they didn't tell me is that I had to start with the breastfeeding and I had to do the pumps and stuff. When I did manage to get her to try and do breastfeeding, the nurses they just grab your boobs, and I'm just like "whoa, hold on" you know "it's just this is all new to me". And if there's somebody in the room and you get so shy and in front of my partner at that age. She never liked it, she hated it, because I mean they give them dummies to suck on and stuff like that. And they're so used to being fed through their nose and stuff and their syringe and there's always a lot going on. I found too that breastfeeding is very exhausting for them especially compared to actually bottle-feeding. It's a different sucking motion. With prem babies, they get tired very, very easily, they can get run down very, very easily.

In terms of how the hospital treated me, well pretty much after they cut me open, got her out that was it really. I was shoved in this cold room by myself and nobody kind of told me anything. I didn't even know. The hospital experience was horrible. I mean horrible, as I said, I didn't get out of bed till the third day. She was in there for six weeks. I was wanting to get out of there so fast it wasn't funny. All I wanted to do was to be home and be with my partner.

As horrible as that sounds, I had been in there for at least two months. And you know, and it was horrible being there. Even though I could go and see her and stuff, I

didn't know how I felt. I was just all over the place. And I was so sore and it was so emotional. When I first got to bath her, when I first got to hold our daughter, when she first opened up her eyes properly, when she made noises. I did not have that support.

One of the positive experiences of NICU was moving from each different room for different stages, the further down the line you got, the closer you got to home. Another bonus was that they had the day stay room. we got staff discount prices for the canteen and stuff like that. And up in the NICU and things like that they had free tea and coffee and they always had food for the mums, the breastfeeding mums and that was good. Some of the nurses were very good. The doctor that I had, that actually gave me the C-Section, he was fantastic himself, he came and saw us on a few occasions to make sure. Like I said I was young, he wanted just to make sure that things were okay. He was good.

The difficult moments. One was realising that I never had a bond, that's something that's different. Don't get me wrong I loved her from the moment I saw her, absolutely and everything else but there was just something missing, and I couldn't get it back. Just having that connection, as soon as your baby first comes out you know you want to touch it and everything else it's that. That bonding, that's what unites a mother and child, and that was taken away from me. And to watch other people touch your child and be told you can't, but for good reasons obviously it was difficult and it was very hard. And the fear that I could lose her.

I know I found it hard to talk, to ask questions and stuff, because I know they're very busy with all the different babies. I don't know how it goes nowadays with the NICU, but if they could actually talk to somebody that's gone through it when they were young. I mean that may make a big difference, I don't know. You know, just make sure that they've got that kind of information and not to feel shy or like shame or embarrassed. Because they're still babies themselves so you have to probe them. When you do have a young Maori person, I think it does make a difference who's there for them. I'll go for the Maori way, for the fact that I find that we have similar backgrounds, so there's more understanding.

## M.

My partner and I are about to have our third child together. Our babies have not lived for long, they both were born with NKH (Non Ketotic Hyperglycemia) a disease which truly affected our babies and us as a family.

The day after my daughter was born, I was concerned that she was very floppy and not waking up. She was not waking up to be fed and I could not wake her to feed. Her breathing became very shallow and irregular so I was transferred back to the hospital so they could check out what was going on. It was like a roller coaster ride, there were a lot of lows, but also a lot of highs.

In the beginning there were a lot of uncertainties and her condition continued to deteriorate without any explanation. We were also accused of physically hurting our baby because they found she had a broken collar bone after doing an x-ray. Every explanation we gave them, they just shook their heads and said it was done by force. In the end I spoke to my midwife who confirmed that she did break baby's collar bone because she was too wide to go through the birth canal. It took 10 days for the doctors to find a diagnosis, by then she had had so many seizures that she was severely brain damaged by the time they could treat her.

Despite the accusations, I believe my daughter received the best care that could be provided by the nurses and doctors at the hospital. The only concern I had was the fact that they would not feed her because they did not know what was wrong with her. I felt that by not feeding her it could have been hindering her progress, so I refused to eat myself until they gave my daughter something to eat.

I feel like I was not communicated with properly. I never really knew what was happening or why things were happening and they were accusing me of physically abusing her and then they wanted to discharge me home and leave her at the hospital by herself. And with my whānau we were given access to a whanau room so our family could visit. Some nurses could be inconsiderate. Some of the nurses didn't like my family touching her, singing to her or the amount of people that came to visit her. No one in my family cared that she was brain damaged, all we cared about was that she was a little girl who was very loved and needed special care and with our big family it could be done.

I think that hospitals should give some thought to older siblings visiting babies in NICU. Children can be more mature than what the hospitals think, and maybe by talking to the older siblings about what they can expect to see. They would be surprised at the way the children act in these circumstances. It would take a lot of pressure off the parents knowing they can be close to their child and can have 24 hour access to them. I thought it was unfair that her older brothers were not allowed to go into NICU as they were under 16. The only time they let us take them in was when they thought she was going to die.

My favourite positive experience was when she opened her eyes for the first time, all I could do was smile and cry. When we discussed her diagnosis, and the outlook of her life, we were told she may never walk, talk, see, hear, swallow or feed from a bottle like a normal baby. 24 hours after we were told that, she had her first bottle and she nearly drank the whole thing. But the best thing of all was taking her home. The worst experience I had with her was when she started having infantile spasms. These were heartbreaking to watch. I think it took me 2 days to recognize them and I knew in my heart there was nothing they could do to help her. Then I watched her slowly drift away, it was horrible.

## Ngā kōrero o ngā whānau : Analysis of Participant Interviews

Interviews undertaken for this project raised a number of areas of concern from whānau in regards to their experiences of Neo-natal Infant Care Units. It is important to note that all whānau were highly appreciative of and acknowledged the clinical care received within the units. For many whānau their babies were in critical states when entering the units and there is consistent comment made in regards to the fact that they are aware that without such medical intervention their babies may not have survived. It is also noted that for those whānau whose babies did not survive there was also clear acknowledgement of the medical care provided and of the significant attempts made by hospital staff to provide high level critical care. Numerous comments were made in regards to whānau wanting to support the medical care and interventions being made by the staff for the wellbeing of their babies.

Given the high level of clinical care provided the research team also acknowledge the role of the various unit staff to work for an outcome that would see a healthy baby leaving the unit and being settled with their whānau in their own homes. This is clearly a collaborative intention on the part of both medical experts and the whānau involved. What was clear throughout the interviews was the contradictory nature of being in NICU for many Māori. On one hand whānau acknowledged the medical care, but often in the same discussion there would be clear issues raised in regards to social and cultural interactions within the units.

*I managed to get through my time in NICU and I'm thankful for all they did for \_\_\_\_\_. NICU gave her the best care. I struggled there but she grew and grew and I'm thankful for that. We're now at home and she's happy and healthy and tracking through her developmental stages well.*

*I mean the medical help they give is world class, it was jus the clash of how we wanted things done and how they did things where we had problems and we didn't really resolve them, we kind of took things day by day but it made for a long ten weeks.*

*The boys were taken straight into NICU and ..... was put straight into an incubator. Their medical care was second to none. He wasn't in for very long, he was in for a couple of days just while he stabilised and with in total while I mean in NICU for about a week. It would have been longer but I wanted to get them out of there because I felt we weren't being really listened too in terms of their care. My GP was quite an influential doctor in Auckland so I rang her and asked her if she would come in and organised to get discharged out of the unit. They were quite a good weight, over the legal weight so there was really no reason for them to hold us there as medically they were fine.*

*He pai pea a NICU mō ngā mama hou kāore i te tino mōhio ki te whāngai i ngā pēpi i tae tino moata mai. I kite māua pera ētahi mama kāore he paku mōhio me pehea ki te pupuri pēpi. He waimarie noku he māhanga a \_\_\_\_\_ nā reira mō te taha ki te tiaki māhanga he waimarie ahau engari kāore pea he painga a NICU ki a mātou i te wā e noho ana i reira, atu i te taha rongoā, ki*

*te hoatu rongoā kia pakari i a rāua. I pai noa iho tā māua, me kī e mōhio māua ka taea tonu ki te tiaki a rāua. Mō ētahi atu whānau kāore mōhio, he tau hou ki te tiaki pēpi kua whānau moata mai ara atu ngā painga ka awahina ngā nehi, ka whakatumia rātou. Me pehea te pupuri, horoi me ērā atu. Engari mō tātou ngā Māori, ngā whānau Māori me uaua kia kite i ngā painga he rerekē ngā whakaaro o ngā rata me ngā nehi. Kāua pea kei a NICU noa iho.*

However, key concerns were raised by whānau in regards to the overall culture of the units and it is clearly identified that for those whānau that identified as Māori there were many issues and situations that arose for them that created additional stress during their involvement within NICU. The following key themes were identified by whānau as key areas of comment or concern.

- Reasons for entering NICU
- Bonding
- Separation
- Accommodation
- Isolation
- Whānau
- Staffing
- Communication
- Tikanga Māori
- Need for Māori Support
- Impact on the home

## **Reasons for entering NICU**

A wide range of medical reasons were given by whānau for entering NICU, however the majority of the whānau interviewed were there primarily due to premature birth of their child/children which meant that there were for all those whānau associated critical medical conditions. Of those interviewed a high proportion of whānau experienced emergency caesarean births, others were induced due to health issues whilst a small number of whānau experienced early labour also due to health reasons for either the mother or the baby. A range of reasons provided by whānau for entering NICU are highlighted here, these are a range of quotes from whānau that provide a good overview of how whānau came to enter units.

*We had our son at ..... Hospital, he was seven weeks prem. I had gestational diabetes so my blood pressure was high and we didn't want to put pressure on baby. I had a caesarean at 33 weeks. He was four pounds, six ounces. He had neonatal hypoglycemia and his lungs were small but he was ok. He stayed for seven weeks being supported with oxygen and increased glucose thru IV.*

*At a routine midwife check, I was diagnosed with protein and severe blood pressure. I was admitted to hospital with suspected preeclampsia and remained in hospital for monitoring. Ten days later, my stomach felt very tight, I alerted staff and a scan revealed I had low fluid in the womb and that I needed to deliver. I had an emergency caesarean that afternoon. My son was born 15 weeks premature. He was 706 grams with sever lung disease. He was rushed to NICU and intubated.*



*I had difficulty conceiving, I miscarried three times. I carried a child to almost six months and had a stillbirth. The cause of the miscarriages and stillbirth are still unknown, it's thought it's a chromosome abnormality. When I got pregnant with \_\_\_\_\_ I was scared the whole time. At 30 weeks gestation I started spotting. I was admitted to hospital and the obstetrician recommended I have a caesarean, that baby's movement had decreased, her heart rate had slowed and that she was struggling. We had a caesarean. It was difficult, we had never kept a pēpi this long and then to see her born and think we would lose her too, I didn't know what I was doing. I tried to bond with her but then I tried to not bond. We'd lost so many babies before it was too hard to know what to do.*

*Our babies have not lived for long, they both were born with NKH (Non Ketotic Hyperglycemia) a disease which truly affected our babies and us as a family... The day after my daughter was born, I was concerned that she was very floppy and not waking up. She was not waking up to be fed and I could not wake her to feed. Her breathing became very shallow and irregular so I was transferred back to the hospital so they could check out what was going on.*

*E rima, e ono mārāma ranei i te wā e whakahua mai ngā rata he māhanga, nā reira mai taua wā ka tino, i te pai tonu ahau i te wā, ka eke ahau ki te whitu mārāma ka āhua raruraru taku tinana e kī ana taku rata... Nā reira ka kawea ahau ki te hohipera ki reira e noho ai tae noa ki tā rāua whānau mai. Nā reira, e rua wiki ahau e noho ana i mua i to rāua whanautanga mai, e ono wiki mātou katoa, me \_\_\_\_\_, me ngā pēpi i roto i a NICU. Nā reira i te whanautanga o ngā pēpi i whānau moata rāua.*

*I had \_\_\_\_\_ ten weeks early, I had pre-eclampsia I think it's called. He was born by emergency caesarean. My sister and aunty were there, babies father wasn't around. He wasn't breathing when he was born, my midwife was really quiet but when he did cry everyone was relieved! He went to NICU and I had to stay in recovery. My aunty went to the ward with him, my sister stayed with me. He had a hard time over the next two days, it was touch and go. I only found this out when I read his doctor's notes. My aunty and the staff just kept saying, he's doing well, he's on ventilation to help him breath. I went down to see him the very next day. He was tiny and had lots of tubes and wires. He was pretty sick. The nurse told me as much as she could, she answered all my questions.*

*I went jaundiced and found out I had Hep B. So we think I picked that up through the hospitals, going in and out because I was sick so much. Because I had full blown toxemia by five months. So just had a lot of health issues there... On and off. She was three months premature.*

*He was having trouble breathing and was covered in meconium so he was instantly put into an incubator. \_\_\_\_\_ and mum said that despite this he somehow managed to rip the mask off his face. He was taken up to the neonatal unit then and mum and \_\_\_\_\_ went with him. There were*

*complications with the placenta so I had to go into surgery to have it removed. The placenta had grown in two parts and was connected by a thin vein. His umbilical cord was attached to the lining of the bag instead of the placenta itself, so the whole thing just fell apart. It was incredible that it had sustained him for so long.*

Given the high number of caesarian sections amongst participants there was discussion raised about the care of the birth mother within the hospitals. It must be noted that comments made by mothers must be understood within the context of not only having to heal themselves but also in relation to having a critically ill baby/babies and being separated from them whilst on the wards. Dealing with having to heal themselves after a caesarian whilst being separated from their child/children was difficult for mothers.

*The care was alright till I got sick and I was down for three days and they found they left the placenta in me. I collapsed and I told them I felt like I was having another baby and they took me for a CT scan and they told me they had left the placenta in me and the couldn't explain why they did it. He said it could have been from when there was so many things happening and I had eight blood transfusions.*

*I do remember throughout all of that [caesarian]... because you can stay awake or not, yeah well that didn't work for me. Because they started cutting and I said "I feel that" and they weren't listening, and I'm like "I can feel it," and they were like "you shouldn't." They'd cut me and I could feel it. That's what I remembered I could feel them cutting. Next time I woke up I didn't know where the hell I was, so I passed out and that's it they just knocked me out after that.*

## **Bonding**

Given the often traumatic experiences that many whānau faced in the birthing process and that their baby was often placed directly into an incubator, it was difficult for some to come to terms with how to touch and bond with their baby. Where holding your new born baby is a taken for granted for many birth mothers and whānau, having a seriously ill or premature baby makes touching and bonding a much more difficult process.

*The first thing I saw were pictures... they wanted to get me up. Because they couldn't take down the bed to go and see your baby, you couldn't get in there. As much as they tried there was only so far I could get and I got to look through a glass window. I was so out of it with the medication and morphine and everything... It was the third day, the third day I remember that was the first time that I got to touch her... well actually no I couldn't... we couldn't touch her, that was hard. I watched the nurses do it, but we couldn't, because she was just hooked on so many machines. It was hard, I just... I didn't know how I felt. You know here was something that was like whoa, is she really mine?*

*Her nappy was hard-case you had to actually fold them over again to try and fit. I've got them in a bag somewhere but there's this little red teddy bear*

*jumper... I took it off a teddy bear to fit her and I was being silly and I laid it on the top of her cot, we went outside or something, came back in and she was wearing it. The staff love dressing them, she fitted this tiny little... she didn't fit anything. I hated putting her back in aye, because we didn't know how to. I didn't... she felt like just a little feather you know, I couldn't feel it. I was worried about hurting her.*

*\_\_\_\_\_ gave her first bath there, look at it amazing. I remember getting growled at that we hadn't bathed her, ... but see you're all naive, you don't know when you touch these little... because sometimes you touch your own baby in neonatal, and was like "you're not supposed to do that." And it was like "we don't know," there's a delicate, precious, little... but what I'm saying is I didn't know what you could do and what you couldn't do. And... I don't know if this was day one or day two but we didn't know... we didn't know you had to change their nappy every... you know. I actually hadn't changed her nappy for the first couple days, they had.*

*Because she was in her incubator with all the gadgets on her and then we weren't allowed to hold her we weren't allowed to touch her anything. She had to just stay before we actually were allowed to get her out, that we were actually allowed to I was allowed to hold her or even feed her.*

*You were not given the option and you were not given the opportunity to bond with her because it was quite restrictive in that unit so they had certain guidelines or rules we had to hear to in regarding visiting hours. You couldn't touch her you know, couldn't feed her and anything like that. So we couldn't even have like from a cultural perspective culturally it wasn't even considered so like there was no we didn't have anything, karakia, waiata couldn't have things like that not in there its because everything was quiet and everything is enclosed so none of that took place you know so really we didn't have a chance to bond with her at all within the next few day's or weeks. I must say though out of probably all of our kids she's been most the most different one aye. ... I don't know it could be to do with the bonding I'm not sure because you know how all our other children have been there not like other paua's but not only paua's they've been alright to go to whānau and everything but with \_\_\_\_\_ she wouldn't go to nobody she just really liked, she feed off me until she was a year old and then I really had to force her off me she was really clingy to me.*

*I had difficulty conceiving, I miscarried three times. I carried a child to almost six months and had a stillbirth. The cause of the miscarriages and stillbirth are still unknown, it's thought it's a chromosome abnormality. When I got pregnant with Nina I was scared the whole time. At 30 weeks gestation I started spotting. I was admitted to hospital and the obstetrician recommended I have a caesarean, that baby's movement had decreased, her heart rate had slowed and that she was struggling. We had a caesarean. It was difficult, we had never kept a pēpi this long and then to see her born and think we would lose her too, I didn't know what I was doing. I tried to bond with her but then I tried to not bond. We'd lost so many babies before it was too hard to know what to do.*

*To rāua whanautanga mai e rua pauna pauna noa iho i a Matariki tata ki te wha pauna a Te Ahuru nā reira tino pakupaku a Matariki rite ia ki te pauna pata. Rāua tahi tae noa kotahi mārama...tata pea e noho ana i roto i te incubater. Ko te kangaroo cuddle, me kii ko te piripoho ki te tango i a rāua i te ahuru mowai. Ka whakapiri ki taku poho kia rongō ai rāua i taku manawa me te mahana o taku tinana. Āhua raruraru anō māua nā te mea te mahere ki kangaroo he pai ake ki te noho rāua ki taua mea whakaahuru i te nuinga o te wā. I te uinga o te wā kia pai ai a rāua tipu kia pakari ai rāua, e rua wā noa iho i te kia taea ki te tango i a rāua me te pupuri i a rāua ki taku poho. He mea tino uaua ki ahau e hiahia ana ahau ki te tangihia rāua i ngā wā katoa. Ka poto rāua ki runga i ahau engari ehara tera i to rātou tikanga, kii taku mōhio he rereke ki te hohipera o te Whanganui a Tara. I whānau moata mai anō te pēpi to māua hoa I mea mai te tino aki ngā mama ki te pupuri i ngā pēpi i ngā wā katoa. Nā reira he rereketanga nui tera i waenganui i ngā hohipera. He ahuatanga me whakarereke nā te mea e mōhio ana ngā mama he aha te mea pai mō tana pēpi. Me kī kāore ahau e āhei ki te horoi i a rāua he pakupaku no rāua kia āhua pakupaku i a rāua kia whai kaha o rāua tinana kia mahana ai rāua ērā mea katoa. Kātahi ahau kia tuku kia rāua nā te aha he tino pai rāua i te wai, tino whakarata i a rāua, kei te pērā tonu inaianei. Ki taku mōhio kāore e pai ki ngā pēpi katoa he koa ki a rāua, he whakarata. Inaianei mēnā e hiahia ana māua ki te whakarata i a rāua ka kaukau rāua.*

Another aspect of bonding that was commented on is that of breastfeeding. Premature babies in NICU are often tube fed whilst in the unit and mothers commented on their desire to breastfeed and the difficulties of learning how to breastfeed a very small baby.

*You had to give 90% like breastfeeding I never had done that. They have these pumps going on and you give it all. They were sucking me out to try and get that boy healthy you couldn't even get a ml out. They were trying everything and it was frustrating but they did.*

*Ki te whāngai ka tino whakamatauhia ahau kāore taku miraka i to rāua whanautanga mai. Nā te āhuatanga ki to rāua whanautanga mai me kī by caesarian. I āhua tōmuri mai taku miraka ēngari e rua rā noa iho te pakeke o son ka whangote ia ki a ia, ka timata ia ki te ngote, whakamiharo ana ngā nehī nō te mea ki tōna tikanga kāore anō ngā pēpi kia ako ki tērā pūkenga te ngotengote. Ēngari e rua ngā rā ka timata ia ki te ngote. Nā reira nā tēnā ka timata taku miraka ki te heke iho. Nā reira i te timatatanga i te hekenga mai o taku miraka ka whangote ki a \_\_\_\_\_ engari ko te nuinga o ngā miraka ka hoatu ki a ia. Kia \_\_\_\_\_ he paku ki a ia ko te nuinga o ngā miraka ka pau ki a ia. Ki a pai ake te rere o ngā miraka kia whāngai ki te wā kotahi. I tino maia ahau ki te whāngai ki a rāua i te wā. Haunga anō a \_\_\_\_\_ tekau mārama kia puta ngā niho.*

A number of whānau discussed wanting to focus on breastfeeding however, the actions of some staff made that difficult, in particular some whānau finding that when they went to breastfeed their baby/babies had already been tube/bottle fed and therefore would not feed.

*They weren't breastfeeding very well and we tried to get them to delay the tube feeding so I could put them on breast first and tube feed them later. I was very clear about them being breastfed but the birthing process was quite traumatic physically for me so I ended up in a ward ever for a little bit longer and it took me until the next day before I could actually physically get down to nicu. I felt like that what we wanted for the babies wasn't listened too. I said I wanted to put them on the breast first and I would get to the unit and find staff had already tube fed them with formula, even when they knew I was coming down from the ward.*

*One of the upsetting incidents we had in the unit was we wanted our son to be breast fed and asked that my wife be woken up to do that, but when I got there they had already bottle fed him. I was angry and hurt and my wife was crushed. For whatever reason they had not rang the ward to get her to come down, I don't know but they didn't. I spoke to the nurse and she said she hadn't been informed to contact us even though we'd told our doctor and the nurse that that's what we'd wanted. Something that was important to us got lost in their process.*

Other mothers also noted that they found the process of breastfeeding difficult and at times embarrassing or painful.

*I had to get my tit squeezed and the milk flowing, cause your milk's not actually flowing. For 3mls, for 3 measly mls I... I remember one night I really tried to squeeze it myself, because it really hurt... I got 9mls and I thought "cool that's three feeds, that's nine hours worth, cause they feed every... went downstairs all proud with it and I went to take it up to neonatal, and they said "oh she's up to 12mls now, 12mls a feed." I let \_\_\_\_\_ feed her to, with my milk but he fed her... they encouraged that aye? They loved the holding they did encourage that. It was actually a nice Māori woman that was there. That came up.*

*Knowing how to look after a child and knowing how to breastfeed. It started off stressful it felt like the nurses were rough with me and I felt like I was slow to learn.*

## **Separation**

Bonding with babies was further exacerbated by separation. Often mothers were on the wards for a number of days healing from the birthing experience and some found it physically difficult to be with their baby. The restrictions on whānau entering the unit also acted as a barrier, as did some of the treatment that whānau received from some staff. In some cases the mother was on the ward, the baby in NICU and for whānau, that did not live in the city where the unit was located, were either housed in accommodation such as Ronald McDonald house or with other whānau. This meant that whānau experienced high levels of anxiety and stress due to separation not only from their baby but also from each other.

*Seeing \_\_\_\_\_ and \_\_\_\_\_ our girl was hard sometimes, I'd leave work and travel down and get there late and the staff would say it's not a good time to visit but I'd just come from \_\_\_\_\_ so I wasn't gonna be turned away but that*

*was the main issue for us. Access was a big one for us. It was good we were only there for a little time.*

*I was admitted to hospital at 32 weeks gestation with low blood pressure, my daughter was born a week later, six weeks early with a cleft palette and breathing difficulties. She was admitted to SCBU \_\_\_\_\_ and then transferred to \_\_\_\_\_ NICU. She was 3lbs 7oz. I stayed in Hospital, her dad went to \_\_\_\_\_. We stayed in contact by phone and text. My partner has whānau in \_\_\_\_\_ so he stayed with them and they supported him with food and transport. We didn't access the support networks like Ronald McDonald House or Winz because Ronald McDonald House was full and we were told she would be there for a few days only, maybe a week. Also my partner isn't really an outgoing person so he found it easier to stay with whānau rather than people he didn't know.*

*I'm glad \_\_\_\_\_ wasn't seriously ill or we'd have had to stay there for longer and that would've been hard. It's a long way for \_\_\_\_\_ to come down twice a week and then to get there and be told by different nurses that he couldn't come in, both times, that wasn't the one. It stressed me out a bit. I didn't know who to talk to about it, I talked to the head nurse and she said \_\_\_\_\_ should come during the day but I said he worked and had to travel after work, she said he should wait till weekends. In the end we didn't stay more than two weekends so we didn't need to find an answer. We just kept on doing what we were doing and eventually they stopped growling us.*

*I stayed with baby for three weeks and then I had to be discharged from the National Woman's and that was the hardest thing for me and leaving my baby in hospital.*

*I traveled back and forth from home. We lived local so travel wasn't hard but it was hard leaving the boys in hospital. I was too tired to stay in the ward all day and night. I had to go home and rest or I'd be too run down. That wasn't easy leaving the boys behind, we asked the hospital if we could set up a roster of whānau and friends to help care for the boys. That took a bit of negotiation, the hospital seemed to have a fixed rule of only parents to visit babies but eventually we talked them around. My sister in law would bring in milk in the mornings and my mum would do it at night. I'd come in mid-morning and do cares and then my partner would come in the afternoons to see them and have kangaroo cuddles. It's a routine we got into for the six or so weeks they were there and it was a big help on us.*

*All I remember was that they were talking about baby, she was in her cot I was in my bed, they were talking and then they just wheeled baby out and I said 'where is she going' and they said 'she is having breathing problems we going to sort it out' and that was that. We were like 'when can I go and see her' ... [staff] need to be clear on what's going on instead of leaving me on my bed frantically trying to call somebody. Because there I am all by myself not knowing where my baby is or know that she's gone down below and I can't see her and I really wouldn't have a clue what they were doing to her.*

*It was really stressful and hard because all you want is to hold your babies and I couldn't hold them because I was in such a state after their birth and then I was in so much pain after the birth it was a real effort to get to the unit. I never thought I would be separate from my babies like that. I just wanted them with me all the time.*

## **Accommodation**

Issues of accommodation contributed to the sense of isolation and separation felt by whānau. Often whānau were split across a range of accommodation and therefore the issue of isolation was also about being separated from each other and the support systems within their whānau. For those whānau that were able to stay in parent rooms the ability to have whānau with them was able to be mediated, however many did not have that option or the parent room was the last move that whānau had just prior to the baby/babies being discharged.

*My diabetes cleared once I'd delivered \_\_\_\_\_ so I was discharged within a week. We lived up the \_\_\_\_\_ coast and so for the last few weeks that he was in hospital I stayed in a parent room at the back of the unit. That was a big help. \_\_\_\_\_ and his whānau stayed home took care of our other kids, while I stayed with \_\_\_\_\_. If I wasn't able to stay in one of the parent rooms, I would've been pretty stressed out. It's a long way to travel from the coast to Wellington everyday. I was able to cook and sleep at the hospital and \_\_\_\_\_ and the kids would come in often. Sometimes when \_\_\_\_\_ really had to go to work and couldn't watch the kids, they'd come and stay with me at the hospital, we could do that with the parent room, they'd hang out watching dvds or playing in the room while I went and took care of \_\_\_\_\_ cares. We'd go for walks to get a break from the hospital. But most of the time the older kids were with \_\_\_\_\_ and Gran.*

*You had a room by yourself or with one other and it was private....you had your own lounge too. Everything was private and the nurses were really good at helping and showing us what we needed to do for baby.*

*There was this end... couple of end bedrooms at the end of where the women stay... there were a couple of end bedrooms, and I found out about them, that you can actually stay there, your own private little room, so you got you own... so I managed to get one of them, which was so cool, I could lock it and yeah it was just good and anyway, \_\_\_\_\_ was really tired once and so I said "just go have a little sleep in the bed, they won't know" but there was this woman who worked behind the desk, she didn't like us... She'd tell him to leave if it was 9 o'clock at night or... anyway I said to \_\_\_\_\_ "just go and have a two hour sleep on my bed, you're knackered," and myself and my other daughter went outside to have a smoke and next thing you know there's \_\_\_\_\_, and she'd gone in there, bashed on the door and kicked him out, chased him out... she hated us. I actually slept in my car one night, cause I was too scared... cause I had really sore feet... and I was too scared... cause it was way on the other side of the car park, the starship's children part, and ... so I slept in the boot of my car, it was quite big. I just couldn't be bothered with the pressure of going to knock on the door and being let in.... And they growled at me*

*because I slept a little bit in the car, and I was half an hour late for a feed. They really growled at me, because I should be trying to get her to breastfeed.*

*Daily we had difficult times. One of the biggest stress I had was the fear of being separated from \_\_\_\_\_. I managed to delay this because I was still a patient and therefore close by. I remained a patient until the final four weeks of his stay and for the last two weeks, I was stayed in one of the parent rooms behind the NICU unit, to prepare for his discharge. I was very lucky. However for many others, accommodation was a stress. Ronald McDonald House helped many as did the private hospital close by but for whānau who didn't live in \_\_\_\_\_, there was this constant fear of being separated from your pēpi because you couldn't afford to live in \_\_\_\_\_.*

A number of whānau noted there was a day room available and many whānau utilized that facility however there was clearly mixed knowledge between whānau as to what facilities were available. Where NICU has a policy of 24 hour access for parents this was clearly determined by staff on any given shift and some whānau experienced difficulty in asserting that right.

*After complications with the birth of our son we were sent to the unit. It was a short stay but, I got kicked out of the unit and had to sleep in the car. Not only did we not want to be there but there was nowhere to stay. We kept our stay in the hospital as short as possible.*

*Kāore, kāore e hiahia rātou kia noho ia i reira, nā reira kāore e hoatu parakete, he wāhi kei reira mō ngā whānau, i mea mai rātou ki a \_\_\_\_\_ kia taea koe ki te noho ki reira engari ka mea atu kare kau he wāhi...he paku wāhi i a rātou mahere kāore ngā matua e ahei te moe ki te taha o ngā pēpi. Kāore rāua e moe ana ki roto taku ruma he wāhanga kāore i te tawhiti. Kāore e tino tawhiti i ahau engari kāore rātou e ahei ana e moe ki tou taha. Taku mōhio kāore ngā matua, kāore ngā hoa rangatira, ko wētahi, e hē, kei te hē tēnā nā te mea I kote ahau ētahi hoa rangatira e noho ana kei te taha i o rātou hoa engari ko ou rātou pēpi kei roto tonu i ou rātou ruma. Nā reira ake nei pea i roto ke rāua i a NICU enagri kāore rāua i toku taha i roto i toku wāhi moe.*

*I think I was there four days before I found out there was a mums room, they had a parent room and I made my lunch at home and I am so over egg salad but I made my lunch at home and I would take it in. It was almost four days before I found out that they had a parenting room and you could make your coffee and you could even get your lunch if you wanted it. It would have meant the world to me I had to buy coffee down there for the cheapest one was 2.50 and I was wild, I can't waste money on coffee but they had a room there and there was free coffee fruit and sandwiches to eat all the time you know. The parents were able to use and they were so busy and understaffed that I just happened to stumble upon it. One of the cleaners I think told me that there was a parenting room and they also had a room there that you could sleep because there were days there that I was so exhausted and not getting much sleep myself and they have a parenting room there. It's a room for out of towners. They can sleep there just for an hour....they let me sleep there for an*



*hour or an hour and a half. But because they are so understaffed there they can't tell everyone that its there.*

*The hardest thing was leaving them there without one of us there. Once \_\_\_\_\_ was discharged our only option was to go home to sleep, and she was exhausted from the birth and I was trying to work to pay the mortgage as well as look after our other four kids. We would stay as long as we could. \_\_\_\_\_ would stay till the night shift came on and then would come home for a sleep and then I would go in at midnight and would take expressed milk in. We hated leaving them for that time but we had to sleep. So when we did leave it was at the beginning of a shift cos we knew the staff were fresh but I would go back in the night as I was there when the staff were starting to get a bit tired and I could do their cares myself. There was nothing worse than leaving our babies there alone without whānau. We would tangi about it all the time.*

## **Isolation**

Separation of babies and whānau led to a number of people referring to an experience of isolation. This took a range of forms, including a sense of increased stress and loneliness both on a physical and emotional level.

*Actually I think I adjusted to everything pretty fast and my main aim was to stay out of their way there was other babies wired up so I sat in the corner way out of their way. Like I say I learnt and I studied the medicine and the machines they were using and I occupied my mind with learning that. Only thing that got me was the long days and no visitors and couldn't get out that was driving me nuts... We had to find our own food and at night we weren't allowed visitors in your room...very lonely and stressful you know.*

*The hard things about neonates for me was the isolation, not having whānau and mates able to help you, it was really just \_\_\_\_\_ and I, and the financial stress of being away from mahi. I tried to get help for \_\_\_\_\_, she was sad and struggling but I couldn't do that from the farm, communication with her was on and off. In the end I'd ring her ward and tell them I was worried about her. I rang the unit to see how \_\_\_\_\_ was doing and after that I took time off from the farm and went to the hospital. I talked to \_\_\_\_\_ about getting counselling, I talked to them about getting her counselling, I talked to anyone and everyone. \_\_\_\_\_ came down and took \_\_\_\_\_ home. We agreed that was the best for her but I got the feeling that the staff thought she was abandoning our baby and that I was domineering. I didn't care, I knew her better than anyone so I told her she need time away. I remember telling the staff that Tarns and I had talked and that we thought it was best for her to go for a break and the nurse said to me she thought she should talk to her doctor. Yea so I was dismissed a bit at first. I managed to talk to a couple of people who finally understood and they talked to doctors and so on. I reckon though if I wasn't older, I could've been ignored by doctors and nurses.*

*What was hard for me was not being able to have a normal baby, not being able to have him on the ward and not being able to hold him. Nothing about his birth was normal, no whānau able to see him and if they did it could only*

*be for a brief moment. It was isolating not being able to tell or explain what was happening. All anyone knew was I'd had a baby but he was severely prem. Isolation was hard, I had all the whānau and I had all the contact with people but others didn't understand a lot.*

*I think when I asked the nurse what is happening where what is happening with my baby and she goes their talking about it, she has to go down the unit as soon as we know you know like we will let you know cause I think for me sitting in my room and I couldn't get a hold of \_\_\_\_\_ and I think I got a hold of my mum and I was quite you know think I was yelling at my mum I don't know what was going on.*

*The neonatal paediatrician told us baby's chances were good, that she was healthy and that with time in the unit we could be ok. We spent 11 – 12 weeks in the unit. I struggled in there, I wanted to be close to \_\_\_\_\_ but I didn't want to get hurt again. I was diagnosed as having postnatal depression but I think I was depressed pre-pregnancy. The nurses and doctors and counsellors and social workers tried to help but I couldn't open up to them. I could only really talk to \_\_\_\_\_ and our closest friends and they were a long way away. I wanted to have more family with me but the unit couldn't and didn't allow for more than a couple of people. I felt isolated all over again. The Priest at the hospital spoke to the charge nurse and even though I'd asked a few times if I could have family stay with me, it wasn't until he talked to the unit supervisor, that I felt someone took me seriously. I think the Māori support staff were pretty busy because I didn't see anyone but then I wasn't opening up to anyone except whānau, so I don't think I would've opened up to them too. When I was discharged, about six weeks after I had pēpi, I stayed with friends of whānau, not an ideal situation. I was isolated.*

## **Whānau**

A key issue raised by Māori participants was the need for a greater acknowledgement and involvement of whānau. Currently Neonatal Intensive Care Units operate on the construct of the nuclear family, which is fundamentally defined as two (heterosexual) parents and biological siblings. For many participants this limited their ability to have whānau support readily available to them. For others the definition of the heterosexual nuclear family meant an ongoing issue of the denial of whānau and in the case of lesbian led whānau a need to constantly assert the rights of their partners and children to be recognized within the unit. This adherence to the two parent family model is one that is asserted in units in regards to safety of the babies and in particular the potential for illness entering into the units. However, it is clear that all whānau were constantly aware of the need for safe and hygienic practices and also the need to ensure that medical staff were not impeded in their provision of clinical care.

*So they took care of the baby and I took care of myself and when whānau visited it was very strict. One visitor per time and only the mother was allowed to be in there with the visitor... You only allowed one and mostly it was the father or a relative that came from far away. There was nothing in place for*

*them you go and visit and then you weren't allowed to sit around with the baby.*

*The hard thing about NICU for us was access for \_\_\_\_\_ and our whānau. It was alright for me I went in and out but \_\_\_\_\_ had to always be let in and was always being asked if he was a parent and if his whānau were immediate whānau members and that we couldn't bring in whānau all the time. We knew we couldn't have a lot of whānau in and out of the unit so we kept it to a minimum but our whānau couldn't always come during visiting hours. The nurses would growl us all the time for having whānau. In the end we just told whānau not to come and that we'd be home soon. We were discharged within two weeks so that made it easier for us.*

*Without his family, we would've struggled but they had no problems giving him the car or dropping him off at the hospital and making him kai. They also went into hospital to sit with baby, give him breaks and give him someone to talk to.*

*We stuck to the two people at a time and so we timetabled people to rotate and everyone involved with us knew that if you had a cold or something you didn't come. Our support people would stay there like four or five hours and then when I would come down from the ward and I would come in. Sometimes we had more than two people just depending who the nurses were but everyone knew or you work out or find out very quickly what the protocols. In terms of cleanliness and washing and all that stuff so everyone knew where I think we wore gowns, everyone knew to wash all the time, not coming in with colds. Everyone knew because you learn that very quickly that for some babies its about life and death. You learn it by doing it, people start saying you must use anti-bacteria, you must wash your hands you must do this you must do that and in our experience whānau are very careful about doing the right things.*

*I can't stress how hard it was leaving the boys there but having my whānau with them made it possible. If not, I'd have been there ten to twelve hours a day and eventually I would've been a wreck. I saw other mothers do that, they couldn't leave their kids, some of them even slept in their cars in the car park just to rest and then they'd go back and be with the kids. That's not easy. I couldn't do that with the twins. It was too much. I didn't really need any social work help, the help I mostly needed was physical support and I got that from my whānau. When the ward let other whānau members come in everyday to help with cares, it made it a lot easier for me.*

*They should take each family's circumstances in to consideration and help whānau where they can. They should also remember that whānau doesn't mean just whānau "mother, father" but also aunties, uncles, cousins even friends. That would make it easier I reckon.*

Two takataapui participants highlighted the difficulties not only in having whānau acknowledged and recognized in the unit but also the added difficulty and issues that arose from being takataapui and therefore not only did they not fit the nuclear family model but they also did not fit a heterosexual family norm.

*Ko tētahi ka raruraru anō ki a māua, toko ono a māua tamariki he rerekē o rātou āhua katoa. I taua wā he tokowha, I ngā wā e haere mai rātou kia kite ai ngā pēpi ka uiui rātou ngā nehi me ngā rata, 'ko wai koe?'..ko wai to mama, he aha ana koe I konei? Ka mate a māua tamariki ki te whakautu a rātou patae e te...me te aha....te whakautu a rātou patae. Kua kuhu atu ai rātou ki te ruma koinei a mātou teina, pēpi. Nā reira i te mutunga koira tētahi mea nui i poia ake, i te mutunga atu naku e kī atu ki ngā nehi koia nei a rāua tuakana anei o rātou ingoa, kua e patae ana anō ko wai rātou, e ahei ana rātou ki te haere mai ki konei. Nā te mea ko tētahi o ngā ture ngā tikanga ranei o NICU, ko ngā matua, me ngā teina me ngā tuakana e ahei ki te haere mai kia kite I ngā pēpi. Nā te rereke o rātou āhua me kia tokowha rātou me te mea anō he takatapuhi māua kihai rātou e tino whakapono. Anō rātou kāore rātou e tino whakapono he tamariki nā māua, nā reira ko ngā tamariki i mate ki te kawē i ngā ahuatanga me ngā rarurau. Nā reira ka taea ke ki te kii ahakoa I ngā rauraru, ahakoa tā māua whakatau, e kore māua e tuku rātou kia pera kei reira tonu ētahi, he mate nui pea kei ētahi o ngā rata kei te hohipera tonu pea, e kore noa rātou e whakatau mahere mō ngā whānau penei i a mātou. Me pehea te kawē i a rātou kia kore ai ngā tu ahuatanga e toko ake. Kāore i te otinga o te ono wiki te tino hoha pai māua te tino hiahia māua ki te hoki ki te kainga. Nā te mea he mōhio māua kia taea ki te tiaki ngā pēpi me to māua whānau.*

*I didn't feel comfortable being there as a Māori parent. I don't remember any Māori nurses or support staff... I don't come from here and my whānau don't live here so we had a lot of friends who came in as our whānau care, who would come in with us. Every time someone new came in we had to explain everything. It didn't fit our family because the rules around family were very heterosexual and very white and its not about extended family. Their idea of family is about mum, dad and the babies, basically that's all it is and we didn't fit that picture so when someone came in to help us it had to be explained again and again.*

Whānau participating both in the care of the child and mother, and in supporting other whānau was noted by a number of participants. Some whānau considered themselves to be 'hands on' in terms of the care and were actively doing things to support that process.

*My mum helped a lot with the medical things, when they needed to take son for tests or the operation on his heart. He had a heart problem with his valve. Mum mostly talked to the doctors, I mostly talked to son. I didn't see a lot of other young fathers. It was mostly mums and older people. There was one other Māori fellah in there at the time, he and his missus were taking care of their baby. He and I would have a smoke in the car park and talk. That was good.*

*Our whānau, is very large and like most whānau, very "hands on". Staff were open to us interacting with \_\_\_\_\_ as much as possible. \_\_\_\_\_ has older siblings who lived elsewhere, they were allowed to visit him where possible. My whānau were able to visit him even during the first critical hours. I later learnt that the ward allowed this to happen, as they were unsure if \_\_\_\_\_ would live but that this wasn't normal practice.*

It was also clear that whānau connected with each other within the units and attempted to provide support amongst themselves in order to help each other through the stresses of having a sick baby. A part of that process was also ensuring that each other knew what support was available to them. It was also clear that those whānau members that had more experience in childrearing saw that for those with less experience or who were younger that they need more support.

*It took a long time for us to settle into the way of the unit. I didn't see a Māori social worker and there wasn't a lot that the social worker in the hospital could do, our main problems were childcare for the older kids and caring for \_\_\_\_\_ but I wasn't going to leave \_\_\_\_\_ there on his own. We didn't have whānau in \_\_\_\_\_. So we just managed where we could. I saw a lot of Māori whānau come thru the unit, some were pretty independent and some needed lots of help, particularly the younger ones. The older whānau, helped the younger whānau too, we'd all have kai and we'd all try and give support and advice, "go see \_\_\_\_\_ (the ward nurse), "go see \_\_\_\_\_" (the support parent woker), "ask your doctor for a letter to show your boss" etc, it was good to help someone where you could, it's about the only thing we could do, we couldn't do any of the medical stuff. It was strange seeing so many Māori whānau there and no Māori support officer. So we became defacto support for anyone we saw.*

*I actually didn't see any Māori social workers, there was a pakeha social worker and she was good, she helped me sort out my benefit and get a grant to help with clothing for pēpi and I. She also helped me with plunket to get a carseat. The hard part in NICU was trying to understand what was happening, I didn't understand a lot of what the doctors said. I understood the basic observation things and I learnt to watch baby instead of the monitors and alarms. The nurses explained as much as they could about what was going on. Also there was a support parent person in the NICU unit. She made lunches for parents and there was a parent support group that met all the time. She was lovely. I met a lot of other whānau through this group so when we were on the ward we were able to talk a lot more.*

*I had a hard time because I didn't have family or my partner to support me but I am a mum of a few kids but anyone else in the same position that didn't have an experience as a mum wouldn't handle what we went through as well as I did. But some of the kids there are the ones that are left there all day and all night and some of the mums don't come you know for whatever reasons you know and they just don't turn up and those are the sicker ones and one nurse per room is really hard, its really hard, they take you on priority there.*

## **Staffing**

Whānau had varied experiences with medical and support staff in the units. As noted previously there is a clear recognition by whānau of the generally high level of clinical care provided by staff and the need to be enabling of NICU staff to do their

job. For some whānau, interactions with staff were positive however for others interactions with staff merely added to an already stressful and tense situation.

*We spent nine weeks in NICU. I was still a patient so I was able to go from my ward to NICU. The staff on the woman's ward and NICU were nice, they let me stay in NICU as much as I could, showed me how to express and freeze the breast milk. Baby was only taking a couple of millilitres of milk then. Baby's problem was her early birth, she wasn't strong enough to leave hospital so we stayed until her full term.*

*I feel that the staff that they had at the time they did their best but I think that they need more staff to help them out there is only so much a person can do and there were times when people didn't turn up to work and they had to get temps on from the temping agencies and I found my baby to be to my standards not looked after, just only my own son I would get there one day and he had a nappy burn and that's just from overnight and then another time when a temp put a feeding tube in they cut the inside of my babies mouth with the tube... But in all honesty they do their best but they need more staff, they need heaps more help at the unit because the staff are really good... But the nurses are really overworked and they needed more staff and they need at least two per room.*

*I had a hard time in NICU, I seemed to be wound up so much, I'd clash with the nurses and with the doctors, I questioned everything they did. In the end I asked my GP to mediate with the staff and I. Thankfully it worked and I got on better with the staff. I'd clash with them over things like I didn't want \_\_\_\_\_ nappies and waste thrown in the general rubbish, I was happy to take it home and remove it but the nurses said that wasn't practical. I said, change your practise. Here's a rubbish bag, put all the waste in here so I can bury it. They found that difficult to do, not to put it in the waste but to change what they'd be doing. But we got around that as much as possible. Some staff didn't find it hard to do, others did. I also didn't want to do all the tests and trials they wanted. Especially the research trials. So I wouldn't give permission. It was a hoha having to opt out instead of the other way around of giving consent. I dread to think how many others didn't know they'd automatically given consent.*

*\_\_\_\_\_ didn't like NICU so we had to do rosters, she'd do the days and I'd go in for nights. It wasn't an easy place for her, she doesn't like hospitals. The staff tried but we had to explain a few times how we'd like things done, we really wanted them to say something to \_\_\_\_\_ like 'kia ora' before they touched him but that seemed pretty hard for them to do. \_\_\_\_\_ would have a go at them for touching him with at least saying what they'd be doing first.*

For those whānau that had access to Parent Support, or who had interactions with staff that were supportive of them and their whānau, this was noted as a positive experience and is clearly one that needs to be more readily available to whānau in the units.

*We went thru weeks of ups and downs, lumbar punctures, blood transfusions, ventilation, operations, tests, tests and more tests. The parent helper at NICU helped a lot with questions, she'd give me books and talk me thru procedures*

*and what was happening, she knew a lot of what happened in the ward so she was really supportive.*

*I had to stay in hospital for a while to bring my heart rate down but that worked for me too, it meant I could stay near to \_\_\_\_\_. The hospital became our nursery. And the best thing was, the nurses taught me how to care for boy. Only the other parents in the ward know what you're going through, mates and whānau would know a little bit but the hard and good times are shared among those who are there in the ward, doing the hard slog. Like when \_\_\_\_\_ wouldn't keep down food and lost weight, I stressed a bit about that and another parent explained the more I stressed the more he stressed. So I had to chill out. I chilled out by going for small walks with the other mums and talking to the parent support woman and going to the support group. That made it heaps easier.*

*There was a nurse there that you felt you could leave your baby with and I fully trusted her and I only knew her as \_\_\_\_\_ but she lived close in my area in Takanini and she would offer to bring me home in my area when her shift was finished but because it was early shift and I wanted to wait for his last feed I did I chose to stay for the last meal and then catch the train. Its really hard to leave your baby there and hopefully you pray that he comes through and has a good night. But there was this one time that I called an angel because she gave me that trust and you knew when you come in that he would be smiling all that day and you knew that \_\_\_\_\_ had been on that shift but she is actually on call and they need her there and they call her back all the time cause she is great she is awesome as I was saying.*

*One of the good things about NICU we had was the nurses support. My partner worked odd hours but he was able to come and go to the ward as he needed. Sometimes the nurses would get him a lazy boy chair and he'd have a nap there. He didn't do that often but it did happen twice when he'd worked long hours and was on call.*

It was also clearly evident that for those whānau that experienced negative interactions with staff those interactions had a direct bearing on how they saw themselves as parents or meant for some whānau that they had to assert themselves in terms of having some semblance of control over the wellbeing of their babies

*A lot of the nurses that were there loved their job... some of the old ones, the way they were with the little babies to get them to sleep and get them to burp. Just the way they were... other ones, it's a job you can tell... you can just tell. You hope they didn't look after your baby. Just the way they... they've been feed and you got to see, where as you get other ones that really care... They had so many people on... different people on different shifts, and you had to notice the different people that came on, and there were some better ones. There were good ones and bad ones... I actually thought that I had to try prove that I did care about \_\_\_\_\_. They made me feel like I wasn't that great a mother because I missed a couple of feeds. That's how I felt, that made me feel so degraded.*

*Nā reira tā rāua whanautanga mai e āhua raruraru matau...I raruraru a \_\_\_\_\_ e tino poturi, e moe ia i te taha o ngā pēpi, i roto i o rāua ruma, ka kii mai tētahi i ona ngā nehi, me wehe atu koe kāore e ahei te moe ki konei ngā mea katoa. Nā reira koirā tā māua tutakitanga tuatahi ki ētahi o ngā nehi o NICU me ētahi o ngā ahuatanga i roto i tera o ngā ahuatanga o te hohipera o Tamaki Makaurau...atu i tērā...mai taua wā I whakatau māua e kore māua e pana ai e tuku ranei i a rātou kia panahia māua mai o māua pēpi...ka noho tonu māua i te taha ahakoa te aha.*

*Like what I can remember is that they just told us 'you can't take her out you have to have a look', you know, you just look at baby and it was pretty scary. It wasn't just that like you were there, it wasn't actually clear enough explanation to us as parents about what that process was and when why it was. All I know was that I can't even remember signing any forms they just did it. When I saw baby again, which was late that afternoon, in that incubator with everything thrust down her nose and when the electros were hooked up to her breathing and that sort of stuff there was no dialogue from that staff what so ever. There was no Māori staff, there was nothing we just had to except what was said based on what they were telling us then trusting they knew what they were doing and that was quiet scary time for us.*

## **Communication**

Appropriate communication between staff and whānau, and being able to access information were two key areas discussed by whānau in relation to their experience of staff within the units. Many whānau felt that during rounds, in particular, they were made invisible and that medical professionals would discuss care plans with little or no interaction with the whānau that were sitting right in front of them.

*I think there needs to be some work done in terms of communication between health professionals and whānau in the system and its not just from my past experience but also from my current experience, because they act as though you're not there. You know, they talk past the whānau who have these babies and it makes you feel like you have nothing to contribute and that you don't get to make decisions about your own babies. Some really serious work needs to be done around how the doctor's in hospital's actually communicate with each other and how to communicate with the whānau and to stand in front of whānau four or five of you and make decisions around your babies and act as though your not ever present is really unacceptable.*

*I had good and bad experiences in NICU. The biggest issue I had was I didn't feel the doctors would explain what was going on enough. I didn't enjoy doctors rounds, the doctors seemed to talk among themselves and not to me and when they did talk to me it seemed simplistic. The boys weren't as sick as other babies so there weren't any big complications with them but the doctors still wanted to order a lot of tests and scans that I wasn't sure I wanted to have done. There was also a trial that if your child was a part of you got a gold star on the chart. I didn't want my babies as part of the trial so I wouldn't sign consent. No gold star for us...*



*They monitored him in an incubator and they watched him 24/7 and I didn't get to see him till the next day and I had him about five o'clock the day before. They didn't tell me anything... They didn't come and talk to me about how baby was doing. I didn't know anything.*

*We as parents, found that if we had cultural issues with staff or medical processes, we were able to raise them. However, we are both confident, well educated people and did not hesitate to meet with whoever we needed to, my concern was often for those whānau who felt uncomfortable talking to staff. While we'd often remind Dr's to talk to us, not about our child "around" us, there were times when staff continued consults, oblivious to parents or whānau around them.*

## **Assumptions**

A number of whānau commented on incidents within NICU that were grounded upon assumptions by staff about how them. Those assumptions can clearly be located within a deficit view of Māori whānau and caused some major issues for the whānau involved. For example one mother noted that she was having a stressful time whilst in the unit and she befriended a staff member who happened to be a social worker. The outcome was that the whānau ended up having to deal with CYFS and prove their parenting ability.

*... she wasn't my Social Worker, we had just become friends and as we talked about something there was good days and bad days for me and when I came out [of nicu] I had CYFs on my door straight away. I couldn't believe it, I couldn't believe it I didn't know the woman was working and she is not my social worker she is just a friend, so when we had sat down together I spoke from the heart. I had bad days like everyone else had and I had good days.*

*... had I had known that I would never had spoken so freely but she was just a woman coming to see to other young girls there and we spoke as friends. That was a big shock and after awhile the woman there all decided to keep quiet and we helped one another really and we knew that that information was not going anywhere. Some of the Pākehā were mongrels there was a lady there for two months and she never had one visitor and she was in bad ways and stressful and all that.*

*They naturally assumed that because our son was in their care and we weren't there with him, then they had the authority to do what needed to be done. We were removed from the equation and were inserted when we either demanded it or when we were present. But we couldn't be present 24hours. I wasn't permitted to stay and my wife was on the ward.*

*I found out later that it was the nurses from neonatal that rung and phoned \_\_\_\_\_ hospital to keep an eye on me because... and it started off with the Listerine in my pocket I was telling you about my tooth ache. And because I don't sleep a lot anyway and the whole hospital dies at 7 o'clock, everybody was in bed. I didn't, I took baskets of things to do, I think I was a bit over-active in the mind because I didn't do all these things, but I had lots of things.*

*I'd go outside and have a smoke and text people or... so they were all just suspicious of me... and when I was ready to go home... I'd been away for three weeks, I was dying to go home, I had another family to look after, they wouldn't let me, I was really miserable, I was crying because... then my midwife told me, because they thought I was on drugs they wanted to test me and my baby. I said "test me, leave my baby alone." But they didn't, then later on... they didn't even apologise to me. Way later after my daughter had had a baby, I went to visit her in hospital I bumped into my midwife and she apologised to me, sort of, she goes "oh sorry about that"...*

*Like the issue about breastfeeding, we weren't listened to at all in terms of those basic things and then being in a lesbian relationship, we were almost like being on show, that's what it felt like. There was one doctors round where a close friends there with the babies and one of the doctors commented on that these twins had come from a lesbian, that their mother was a lesbian. I couldn't understand why that would be important because what kind of bearing would that have on their health care. My being a lesbian had nothing to do with their medical care. Then, having people understand that there are two mothers and there is a father, but he's not the parent in terms of the care and so dealing with that kind of ignorance around our whānau and then dealing with that homophobia of some people or some nurses and I know now that there were lesbian nurses working there they weren't in the area we were in.*

## **Tikanga Māori**

For many participants and their whānau, having elements of tikanga Māori included in their stay was important. This ranged from having whānau acknowledged to having karakia through to having staff within the unit being mindful of the tikanga that many whānau operated within in regards to the care of their baby/babies and how they approached that care. It was clearly highlighted that knowledge of tikanga was extremely limited and with having little contact with Māori support workers meant that whānau had to facilitate those processes themselves.

*No my dad had to actually and he is in the book he had to actually go and ask the nurse when he came through if he could give baby a blessing prayer when he came through to give some water. At first they refused and dad felt really say that they wouldn't take just a dabble and they refused and I said dad you can bless him in your mind. So dad got a bit sore about that. He wanted to leave something but your not allowed to leave anything in here because of all the wires running and that.*

*I remember one time when a whānau arrived and you knew they're baby was at risk of not surviving, you knew the signs of what was happening, the closed door whānau meetings, the many many doctors who were there all the time. This whānau were so overwhelmed, we (the parents in neonatal) who were able would make the cuppas in the parent room. It was different talking to us because we had babies in the same position, we were able to comfort them a little bit. They're baby did die, it was hard for every parent in the unit when that happened. It was especially hard for the Māori there. You don't like to*

hear the waiata and karakia and know what was happening but be a stranger on the outside. Tu one of the other parent's did a karakia whakanoa, for the ward and for those of us still in the ward after the whānau had left. We mostly just did it all ourselves. Ae there was a minister in the hospital who could've done it I spose, but we never contacted him, we just did it ourselves. We didn't ask the ward, we didn't ask the nurses or doctors, he just had a karakia where baby had died and we all sprinkle water over the room and ourselves, even the asian couple who were also in that room sprinkled water over themselves and their baby.

There were a lot of staff to help, something's they helped with were good, others I'd change, like we wanted to bless boy and we could only do it with a small roopu so everyone else stood out in the corridor and had karakia. That was a big one for my whānau. They needed boy to be blessed as soon as possible but he was so sick not everyone could come in. In the end the minister and my nan came in, the rest of the whānau waited in the hallway. While our minister was there another whānau were in there and they just lost their baby. He went from blessing \_\_\_\_\_ to having tangi with this other whānau. It was hard. I didn't want to be there while they were grieving. I think that was the only baby who died while \_\_\_\_\_ was in NICU. Well it's the only one that I remembered, I tried not to be around when I could feel things weren't going well for a baby and their whānau. It was ok for me I could go back to my ward.

You know what I mean from a professional perspective like unless you pose yourself on to these non Māori practitioners whatever there's no cultural component cultural act in the birth you know for example my granddaughter was born you know she was there was a karanga done for her and there was karakia you know all of that went on and that only happen cause we implement that not because those staff asked for it but because it was something that my moko karanga into this world you see and that their was a karakia after it and that's how it should have been with our other kids when our own children were delivered that option should have been made available to us and that never was and once they are born they are taken away then brought back to you after they you know. We just had to accept what that moral of the delivery service was which wasn't a Māori it was purely a Pākehā type of service. And because you know as Māori we are whakama about a lot of things and are like. Mind you we didn't know there were Māori practitioner I've never ever seen Māori practitioner's.

*Tokorua ngā pēpi i mate....he Māori...nā reira i kite a kanohi māua kāore kau he tikanga hei tiaki i te kirimate me kii ngā matua me te whānau pani. Kāore ngā tikanga hei tiaki i te pēpi kua mate. Rite tonu ngā takuta mai te kopa moe o te pēpi mate ki tētahi anō kopa moe mō tētahi pēpi e ora tonu ana. Nā reira kare kau ngā tikanga hei tiaki i te whānau, hei tiaki hoki i ngā rata me ngā nehi hoki.*

One positive action that happened was, we asked to recite \_\_\_\_\_ tohi (Dedication ceremony) at his incubator. We asked to have it before day break and that we have as much privacy as possible. After talking through the

*process with the charge nurse for that shift (a pakeha male nurse, Darcy) he agreed to help us as much as he could. He made it clear we couldn't remove \_\_\_\_\_ as he was only 72 hours old and was still critical but that for the brief ceremony, he would tell his staff what we were doing and if they could remain as quiet as possible. We arrived at about 4.30am, the lights were dimmed as was normal for that hour. Staff were aware of what we were doing and were happy to let us go about our business. Under normal circumstances, Tohi can be complex ceremonies, in a neo-natal intensive care unit, the difficulty was considerable. However, Staff aided us as much as possible with their respect and awareness. Thankfully, that early hour of the morning allowed the tohi to occur without disruption to the unit's schedule. The tohi was completed successfully, much to our relief and many thanks to the staff. There wasn't a big deal, there was one conversation between ourselves and the staff and it was completed successfully. We found that certain staff were fully supportive of our cultural needs particularly if we took the time to discuss them with them.*

*An act that affected us negatively was regarding \_\_\_\_\_ pito. One night the pito came away and the nurse discarded it. When we arrived in the morning we asked where his pito was, the nurse said it fell off and she'd thrown it away. We were so upset. We searched as much of the rubbish in the ward as we could, we even went to where the rubbish bags were, however we knew it was pointless, this was our needle and the haystack was enormous. We told the nurse that the pito was a significant part of our culture and that by discarding it we'd lost a sacred part of ourselves. We had a meeting with the head nurse in hope of educating her and her staff about the pito. We didn't believe that just because the nurses were specialist neo-natal practitioners, or in this case, from another country, that they should not have an awareness of cultural practices. This incident was heartbreaking. The head nurse agreed that she would inform her nurses about the importance of keeping the remains of the naval cord for future whānau. We berated ourselves for assuming that staff were aware of cultural practices, we berated ourselves for not putting notes on his incubator regarding his naval cord. Our disappointment in ourselves was pointless, it wouldn't change what had happened. To this day we still feel loss and disappointment.*

A lack of te reo Māori knowledge amongst the staff was also noted. One participant indicated that they tried to have staff greet their baby however very few did that, whilst another participant noted the difficulty in having some staff pronounce the names of their baby twins.

*We had the best medical care at NICU. Staff were highly competent in any addressing \_\_\_\_\_ medical needs but we were often at odds with staff regarding our views on how we'd like him cared for. From the earliest stages, we asked staff to mihi to \_\_\_\_\_ before they worked with him, such as "Kia ora \_\_\_\_\_, my name is xxxx and I'm going to turn you over or do your cares" We put notes on his incubator asking people to please say 'kia ora' to him. We were told staff often talked to the babies when they worked with them and we observed them doing so but it was irregular and there was no recognition of his culture. We knew it could have been perceived as a tokenistic nod to*

*hiss culture but as with any other person, this is how we'd acknowledge them and so wanted this to continue with him. This wasn't always successful.*

*A lot of staff wouldn't say their names, because their names were too difficult for them and many wouldn't make an effort. Māori names are important to us, their names are tupuna names... They would just say the \_\_\_\_\_ twins or just the twin's, twin one or first born whatever because they would have this constant thing that their name's were too difficult for them. We would keep telling them how to say their names but with every new shift we got new staff and we would get the twin one and twin two thing again, even though immediately on their birth they were given their names. It doesn't help to make people comfortable when you are dealing with the stress of sick babies and then having to also deal with attitudes of some staff in terms of cultural things like saying their names.*

### **Need for Māori support systems**

Very few participants received any direct contact with Māori staff. The majority noted that they did not see any Māori staff or any Māori liaison staff whilst in the unit. It is clear that there are some whānau who do not need to have Māori support as they have their own support systems, were able to negotiate the hospital system themselves or positioned their issues as being health issues rather than cultural issues.

*There wasn't a Māori support person on the ward but there are Māori whānau workers in the hospital I got a pamphlet about them but I didn't need to contact them and they didn't visit, we were fine though.*

*I didn't see a Māori social worker at the hospital, I had a pakeha social worker, she was lovely, she helped me with my study courses at tech and had the books sent to the hospital. That helped a lot. I dunno if it would've made it easier if there was a Māori support person, they can be pretty useless sometimes, they can be good to when you don't want someone sitting on the table and all that. Or when you don't want the nappy bin right next to the incubator arrgh that was a drama. It wasn't a cultural issue, it's a health issue. I'm not playing the cultural card.*

Where stays in the units ranged from two days to 12 weeks most participants highlighted tht not having access to Māori staff or support systems is a critical issue that needs to be engaged urgently. It was noted by some that even when whānau specifically requested Māori support that was not provided.

*We didn't have any Māori support group. They did every now and again when we were shoved into Starship there was one lady now and again when we were walking around Starship.*

*I had a couple of meetings with the ward director about my issues. Sometimes we'd reach a resolution, other times we'd disagree. I remember saying to her one day, there's a lot of young kids here that need help especially with money, she said that's what the social workers were for, I said you need Māori social workers cos these kids aren't responding to the ones you have, she said she'd contact the Māori whānau workers but we never saw any of them.*

*At National woman's he received really good care the nurse were good and at that time I was really financially stuffed and I had two other kids at home and we had no help or funds. When I did ask there was someone from the whānau co-ordinator there and they didn't even come and see me at all and I had no help. I had to ring through on my phone to my case officer and I had no money and there was no one looking after my other kids.*

*We were in and out as quick as we could. We didn't want to be there initially and when we were there, our experience was so bad we wanted out. We weren't listened to and we weren't supported.*

*It sort of came down to be like not being informed and like what \_\_\_\_\_ was talking about now is all those sort's of things and date's and time's and day's. I mean it was no different to being in that hospital we were not informed at all I was told, I was told baby was having respiratory problem's that was it you know like I wasn't informed about what's what they were going to do. So the specialist was going to be involved I had pretty much had to accept what ever they were doing like there ignorance and so we had no cultural liaison person we had no contact with any Māori staff in hospital.*

*We all know NICU's are enormously stressful places for parents and whānau. I often saw young Māori mother's, father's and whānau who were left floundering ,while having to deal with critically ill child. Yes there were social workers who tried to alleviate stresses and WINZ staff often met with whānau and these stresses aren't exclusive to whānau Māori, however I saw that it was more difficult for whānau Māori to engage available services for help. In the entire four months \_\_\_\_\_ and I were in hospital, I never saw a Māori social worker once.*

*At the time I was there they had a lot of Indian staff there and for others they would find it hard to pick up on them but for me I have Indians in my family and I can oick up on their accent. To a hard core Māori they wouldn't understand and if they have a Māori staff there it would be helpful and you trust them more. As a Māori you would respond to Māori more and they know how to respond to you more. The Palagi ladies they are more mechanical and they respond differently but for a Māori to a Māori you can say things and they accept it. I am not trying to be racial or anything I would have responded more to a Māori. You know there's things like when my son was born I had to ask for the afterbirth that's just our tradition. If you have more Māori staff I wont have to ask for it but I did. But definitely I support Māori. I am lucky to be strong to do what I did. That unit lacks in staff and to have Māori staff it would be awesome and I know that the unit would be much better off way better off.*

One whānau that transferred from a regional unit to that in a main city noted that their experience in the regional unit was one where they had access to a lot of Māori support workers, who were consistently in touch with them, however in the larger hospital context they did not receive that support.

## Impact on home

It is not only the experiences within the unit itself that impacts upon whānau but there is often considerable stress placed on the home context. Having to spend long hours in NICU with sick babies places a huge amount of stress on the overall lives of whānau. Work and financial requirements can mean that whānau support is stretched and that often partners are rushing between jobs and the unit at all hours of the day and night. For those whānau with other children there was the ongoing stress of ensuring their needs were met and that they were well cared for at home.

*I don't know how to answer that. It was just a really horrible time. Put stress on our relationship and the relationship with my other daughter... it was just really hard being away from home. And being where they made me feel like a bad parent for leaving her for two... I mean they fed every two hours. And every feed is like 100mls, oh no 50 mls or something... I would have so many of those jars with my name on it and they last for four days... I had lots of milk. I mean I was covered... there was not mush of them to feed. I mean they fed other peoples babies... but I felt I was so bad if I missed a feed. I would warn them and say "I'm going back to \_\_\_\_\_ for the day after this feed" and I'd miss two feeds, that means I've got seven hours to drive to \_\_\_\_\_, do lots of housework and come back.*

*It was very, very stressful, very stressful because I had three other children and it was having to organise two children at school and a four and a half year old I had to take with me every single day to the hospital for the feeding and the bathing you know the normal thing that you do with baby and come home with my four year old on the last train on the nine o'clock ten o'clock feed so we were getting home at 10-10:30 and that was really hard and really stressing you mean 10:30 yeah 10:30 at night and we were lucky that we could have dinner and I could put the kids down like my little one and I had to sponge him because I had no time to bath him and then I had to do my housework. And go to bed at about two in the morning and then get up about 6:30 cause I had to make the breakfast and get the kids my other two kids off to school and then catch the train and that was our routine. I lost so much weight that it wasn't even funny but it was beautiful but it was really hard and really, really stressful because I had no family and family support and I had to get their dad the childrens dad to come and stay here after he finished work which was 1:30-2pm he had to come all the way from \_\_\_\_\_ to come and get the kids from school and wait here for the older two children till I got home at 10 o'clock at night which was lucky, and I was really grateful to him because he would have our tea ready and then I would do my normal housework and washing and stuff and then go to bed about two in the morning and then he started work at 4 and that was our day it was horrible and it was hard and it was really really hard.*

Whānau talked of the difficulties of holding their jobs due through their experience but also having difficulties in keeping and maintaining their homes. It is clear that the stress of having long term stays in NICU were often felt in significant ways for the wider whānau at home.

*A social worker came and helped me with the dole. I had to quit my job so I could stay with boy but that's ok I didn't really mind. The ex couldn't express a lot of milk so they had to feed boy with powder plus the ex was still too sick to come and be with him a lot, it was mostly mum and I. Mum had to come back to Palmy after the first week but she'd come down on the weekends. That was good cos she'd give me a break. The ex's mother came down a bit too. I didn't really have any whānau in \_\_\_\_\_ they all came from up the line though. The hospital people helped me, the nurses and that. If I needed anything else I'd ring mum and an Aunty, she'd come in whenever I needed.*

*When I did get out I lost one of my homes when I was in hospital and that's how come I ended up getting a housing corp house. The woman came right to the hospital and took me to the review of the tribunal court. I found it so hard, they said do you have anything to say and I said the doctor at \_\_\_\_\_ hospital gave me this letter and it explained where I had been for four months. The judge just threw it out the door and said to the lady she will stay on in this house for two weeks rent free and she will only pay you five dollars and I didn't have to pay for the four months. Didn't bother me to lose the home when I wasn't even there, so he threw it out and gave me two weeks and then I found this home. He asked me why didn't you say and I said I didn't even know she was coming for the rent and I didn't even know that it was that bad and I didn't even know what I was coming here for.*

*I had to go home... you know I tried to go home and clean the house, it was just getting really a joke. Poor old \_\_\_\_\_ was going to work at 3 o'clock in the morning and being his first born child, he'd go straight to the hospital to spend time with me and baby and then go home to \_\_\_\_\_, and the children needed to be fed, the house was a mess. It was really hard on all of us. It took us a couple of years... well just getting over the damage.*

*It got a bit hard financially and work-wise when baby was still there after the first week. My partner had to take more time off work so he was worried about his job and income.*

*\_\_\_\_\_ came down on weekends when he could but most of the time we had no where for him to stay. I honestly think I would've been better off going home and recuperating rather than putting more stress on pēpi and I by staying. Around week eight of baby being in the unit I did go home, initially for a break but I ended up staying there. My mum came down to be with baby and she sent me home. Boy did I feel guilty. I was lactating and I wasn't with Nina, I felt like I couldn't win either way. I also think and it wasn't how it was but I thought \_\_\_\_\_ resented me for not being strong enough to stay there with baby. In the end he took a bit of time off to go and care for her. He was the one who actually brought baby home.*

## **Summary**

As is clear from the experiences that whānau have shared that the clinical care provided to their babies was the key focus for their entering into the NICU



environment. The reasons why whānau entered NICU were multiple and often due to complex prenatal or birthing issues. There is no doubt that for many there were significant medical issues during pregnancy that increased the possibility that they and their baby/babies would enter into NICU, however there was little access to information provided prior to the birth. Those that did have some knowledge of NICU were those that were on the wards prior to giving birth and where the risk of medical issues arising were evident. The one whānau that were highly informed noted that this was the case because they knew a senior staff member in the Unit and she provided them with an overview of how NICU operated and the possible issues that could arise. Where some antenatal classes discuss NICU it is evident however that on the whole whānau entered into a life and death situation with little or no information about what was to come.

The impact of that lack of information lead to many whānau highlighting issues of bonding, separation and isolation. The experience of having a baby/babies in critical care is devastating for whānau. Often their first contact is through the side of an incubator, surrounded by medical equipment and physical contact is limited. The impact on bonding for some whānau is clear. This is further exacerbated by separation, both between whānau and baby and within whānau themselves. Many whānau commented on the isolation they experienced due to being separated from their whānau and their wider support. Such isolation adds to an already extremely stressful context and there are limited options for whānau in terms of accommodation and access to the units. Whānau spoke of the how difficult it was to access NICU and how there was little consistency amongst staff in regards to whānau access. The lack of knowledge amongst medical staff about what constitutes whānau is clear and the power relationship that exists between staff and whānau clearly mitigates against most whānau feeling heard or listened to. The majority of whānau interviewed highlighted this as a key issue and it points to limited understandings and knowledge of medical staff. This is further increased when information exchange and communication between staff and whānau is limited. Many whānau felt marginalized in terms of being properly informed by medical teams. Some noted that during rounds the clinical teams would talk as if they weren't present. Other whānau worked to find out any and all information they could through whatever source they had available to them. Working together within the units meant that whānau would share their experiences and knowledge with others in the unit in order to support each other. Support between whānau was seen by many as a key way in which to gain, and provide, information. This was seen as particularly important for younger parents who were in the unit, who did not feel as able to approach staff about what was happening for their babies.

A critical relationship within NICU is that between staff and whānau. Whānau recognized that medical staff needed to the space and support to provide the clinical care required and often commented on their efforts to keep out of the way so that staff could do what was required for their child/children. Participants highlighted that positive relationships with staff members led to increased information and access. It enabled a greater facilitation of whānau to knowledge and to feeling comfortable in their experiences within the unit. However, negative relationships meant that whānau felt marginalized and uncomfortable. In particular cultural needs and practices that whānau wished to undertake were made more difficult if there was any negative response from staff. Those whānau that were able to access support staff noted that

their access to information and resources was enabled by knowing who and where to go and they would then share that with other whānau in the unit. A lack of cultural knowledge and training on the part of some staff was highlighted through the interviews and it is clear that there is a need for increased training in regards to how staff interact with whānau Māori. Alongside that need is also a need for training related to beliefs and assumptions about Māori. A number of whānau talked about the impact of people's assumptions that are based within deficit views of Māori.

Another key point made was regarding the lack of Māori staff involved with NICU. Few whānau had any contact with Māori medical or support staff. Even those whānau that directly requested contact with Māori support staff did not receive that. Not only is the lack of Māori staff in NICU an issue but there were also key points raised in regards to the limited support by staff in regards to tikanga Māori. Even fundamental elements such as pronouncing a name correctly or greeting a baby before treatment were not adhered to by the majority of staff that interacted with these whānau. It is evident that individual staff would make an effort in terms of supporting whānau to undertake karakia and a range of other tikanga however that support was entirely reliant upon the staff member present at the time. This raises an issue in regards to hospital policies regarding cultural knowledge or practices. Whānau were, without doubt, cognizant of the need to ensure they did not impede the ability of staff to undertake their clinical duties. All whānau acknowledged that within their kōrero. However, not all staff were as accommodating when it came to whānau undertaking cultural and spiritual practices with their babies. Where whānau interactions with medical staff were mixed it is clear that positive experiences within NICU were on the whole associated directly with positive interactions with staff. This is an area that needs to be addressed as it is an area that determines the overall experience of whānau within NICU. Those whānau that engaged with staff that were positive about them and their baby, and who were open to communicate and share information and who open culturally, were significantly more likely to express positive experiences.

The stress for whānau was not only limited to the unit but extended out to their home context. The impact on the home was noted by whānau. The care of older tamariki, keeping their homes intact, maintaining employment and financial stability and maintaining whānau relationships were all commented upon. For those that had babies in NICU for long periods of time this was a particular issue.

What is clear from the overall research is that there exists limited research in the area of Māori whānau and NICU. The International literature highlights a range of issues that also resonate with whānau however the cultural issues are not discussed and there remains an assumption that whānau experiences match those of other families. This is clearly not the case. Further research remains necessary in regards to more specific detail as to what actually does work for whānau and that would require a much broader and more national approach. There is also research required in regards to the clinical care provided to whānau and an exploration in regards to whether whānau Māori receive medical and clinical care equitable to non-Māori families within NICU. Given the mortality rate for tamariki Māori the research team believes that some urgency needs to be given to these research areas in order to enhance the overall wellbeing as is currently articulated through policies and models such as Whānau Ora.

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