

Insights into the Experiences of Mothers and Birthing Parents known to be Poorly Served by the Maternity and Perinatal System (Technical Report 3)

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Confidential

Insights into the Experiences of Mothers and Birthing Parents known to be Poorly Served by the Maternity and Perinatal system (Technical Report 3)

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CONTENTS

[CONTENTS 2](#_Toc127768172)

[1.0 Executive summary 5](#_Toc127768173)

[2.0 Introduction 9](#_Toc127768174)

[2.1 Background, research purpose, and objectives 9](#_Toc127768175)

[2.2 Methodological overview 9](#_Toc127768176)

[2.3 Report notes 10](#_Toc127768177)

[3.0 Midwife experiences 11](#_Toc127768178)

[3.1 Finding the right midwife 11](#_Toc127768179)

[3.2 Positive midwife experiences 13](#_Toc127768180)

[3.3 Negative midwife experiences 16](#_Toc127768181)

[4.0 Antenatal services 20](#_Toc127768182)

[4.1 Access to antenatal classes and Hapū Wānanga 20](#_Toc127768183)

[4.2 Access to scans 23](#_Toc127768184)

[4.3 Outpatient specialist care experiences 26](#_Toc127768185)

[4.3.1 Positive experiences 26](#_Toc127768186)

[4.3.2 Negative experiences 27](#_Toc127768187)

[5.0 Hospital experiences 28](#_Toc127768188)

[5.1 Positive experiences 28](#_Toc127768189)

[5.2 Negative experiences 28](#_Toc127768190)

[5.2.1 Feeling frightened and vulnerable 28](#_Toc127768191)

[5.2.2 Feeling unwelcome 32](#_Toc127768192)

[5.2.3 Not being listened to and feeling pressured 33](#_Toc127768193)

[5.2.4 Unmet needs 34](#_Toc127768194)

[6.0 Postnatal services 41](#_Toc127768195)

[6.1 Midwifery postnatal home assessments 41](#_Toc127768196)

[6.2 Education and support services for new parents 43](#_Toc127768197)

[7.0 Suggested service improvements 45](#_Toc127768198)

[Appendix A: Methodology 50](#_Toc127768199)

[Appendix B: Discussion guide, Information sheet and Consent Form 55](#_Toc127768200)

Definitions

**Māori mothers and birthing parents** – self-reported.

**Pasifika mothers and birthing parents** – self-reported.

**Young mothers and birthing parents** – aged 24 years or under.

**Disabled mothers and birthing parents** – a respondent was defined as disabled based on their response to the short version of the Washington Group Set of Disability Questions.

Foreword

Te Whatu Ora would like to thank the participants of this qualitative research who generously shared their time and experiences. Their views and comments have provided important insight into the diverse and personal experiences of whānau within the New Zealand maternity system and will inform future service design and planning.

1. Executive summary

**IMPORTANT NOTE:**

The timeframe of this research is important when considering the results of this qualitative research, given that the antenatal, birth and postnatal care of the mothers and birthing parents who took part falls within the period impacted by the COVID-19 pandemic which had a significant impact on the health sector, as well as New Zealand society in general.

Introduction

This is the technical report based on qualitative research completed with mothers and birthing parents known to be poorly served by the maternity and perinatal system.

The overriding purpose of this qualitative research was to provide a deeper understanding of mothers’ and birthing parents’ experiences of maternity and perinatal services, to help identify and inform service improvements.

Learning about these mothers’ and birthing parents’ lived experiences of maternity and perinatal services provides rich insights into what maternity and perinatal services look like from their perspective, when they are working well and not working well, including when cultural, identity and other needs (e.g., physical) are met and not met; the barriers to service access; and what improvements they want to see.

To meet this objective, a total of n=24 mothers and birthing parents from population groups known to be poorly served by the maternity and perinatal system (viz. Māori, Pasifika, LGBTQ+, young, and disabled mothers and birthing parents), participated in mainly small online group discussions, between 31 August and 28 September 2022.

Research findings

The key findings of the qualitative research are as follows:

1. **Positive midwife relationships helped mothers and birthing parents to feel safe and empowered throughout their maternity and perinatal journeys**.

The mothers and birthing parents who participated in this research defined positive midwife relationships in terms of having a ‘good connection’, and a high level of trust.

Midwives were valued for their roles as educators; translators; guides; advocates; and a life buoy (if needed); as well as for being accessible and affirming.

Continuity of care from a midwife appears to improve satisfaction. When care was received from a team of midwives, mothers and birthing parents more often reported communication issues and found it difficult to develop a ‘good connection’.

Other sources of dissatisfaction included midwives not being available, not fulfilling their role as educator, and not being respectful.

1. **Some mothers and birthing parents experienced barriers to accessing antenatal classes/Hapū Wānanga, scans, and support services for new parents.**

Wānanga and antenatal classes that were well run and targeted specific community groups (e.g., young Pasifika mothers and birthing parents) were much more likely to be enjoyed and valued by the mothers and birthing parents who participated in this research, when they were attended.

Key barriers to starting and continuing antenatal classes and Hapū Wānanga included these not being provided at times that were convenient (especially, in terms of fitting around work); long travel times; not being well advertised; mothers and birthing parents not thinking they were eligible to attend; a poor fit with classmates; and the course not being well run.

The most significant barrier to having ultrasound scans identified by the mothers and birthing parents participating in this research was **cost**. Other barriers included confusion about which providers were subsidised; limited appointment options; booking process variations between providers; having to go to scans alone because of COVID-19 related restrictions; and dealing with sonographers who were perceived as uncaring and insensitive.

This study suggests there were no barriers to accessing Whānau Āwhina and Well Child Tamariki Ora, as signing-up was reported to be easy, but some mothers and birthing parents were disappointed with the frequency and number of home visits they received.

1. **Some mothers and birthing parents reported negative experiences while in hospital for the birth of their pēpē/baby.**

Most research participants reported positive or very positive experiences in relation to their midwife’s involvement in the births of their pēpē/babies.

This included those who had extended hospital stays (e.g., because of pregnancy complications or because their pēpē/baby needed extra care).

Mothers and birthing parents who reported less than satisfactory hospital experiences, said these resulted in them:

* **Feeling frightened and vulnerable.** (For example, because: they didn’t trust the system; they experienced the hospital environment as non-inclusive; they were left alone for a long period of time; they did not feel properly prepared for birth).
* **Feeling unwelcome.** (For example, because: they did not fit-in; staff were perceived as insensitive and unhelpful; they felt pressured to leave the hospital before they were ready).
* **Feeling pressured**. Some young mothers and birthing parents reported feeling pressured in their decision making (e.g., to have a COVID shot, to breastfeed, to start birth control).
1. **Negative hospital experiences included unmet cultural and identity needs.**

Examples of the **cultural needs of māmā Māori** mothers and birthing parentsbeing unmet in the hospital environment included, needs being assumed; requests to meet needs not being followed; demonstrations of a lack of cultural respect.

Examples of the **identity needs of LGBTQ+ mothers and birthing parents** being unmet included, being constantly misgendered; having to justify actions outside of the hospital norm; being exposed to non-inclusive heteronormative and cisnormative language; and non-inclusive physical spaces.

1. **Follow-up care and support.**

Mothers and birthing parents who participated in this research and had a ‘good connection’ with their midwife reported feeling as if they were well supported during this period.

Some of those who had been under hospital care expressed dissatisfaction with the follow-up support they received because they were not told they would not have postnatal care from the community team; they did not get any follow-up postnatal assessments at home; or if they did, there was no, or a poor ‘connection’ with the midwife who visited.

**6.** **The mothers and birthing parents who participated in this research suggested the following improvements to current maternity and perinatal services:**

* **More community LMC and hospital midwives** (including Māori, Pasifika, and LGBTQ+) and better staffed hospitals.
* **Make services more inclusive.** For example, by treating everyone with compassion and respect; always asking about cultural, spiritual and identity needs; by providing cultural training; and by using inclusive language.
* **Address the power imbalance.** For example, by making sure that mothers and birthing parents are fully informed before making decisions; that they understand that they have choices; and that they understand that their choices should be exercised without feeling pressured.
* **Support more birthing options** within hospitals, for those who want but can’t have home births. For example, a ‘safe’ hospital-based home birth option and a hospital-based Māori cultural birthing option.
* **Identify and remove the barriers to accessing services**. For example, cost and access to scans, access, availability, and advertising of antenatal classes and Hapū Wānanga.
* **Improve information quality**. For example, by developing more information on the platforms that appeal to younger mothers and birthing parents (e.g., YouTube, Apps); ensuring printed information is up to date; that the language, and that the look and feel of information is inclusive.
1. Introduction

## Background, research purpose, and objectives

Insights into the Experiences of Mothers and Birthing Parents Known to be Poorly Served by the Maternity and Perinatal System is part of a wider research programme. This includes the 2022 Survey of Whānau/Families’ Experience of the Maternity System and Survey of and Qualitative Research with Whānau/Families who have Lost a Pēpē/ Baby.

The 2022 Survey of Whānau/Families Who Have Lost a Pēpē/Baby is the third time this survey has been completed. The 2022 Survey of Whānau/Families’ Experience of the Maternity System provides the sixth assessment of mothers’ and birthing parents’ satisfaction with maternity/perinatal services. The qualitative research with both mothers and birthing parents known to be poorly served by the maternity and perinatal system, and with bereaved mothers and birthing parents, is the first time such research has been undertaken.

The overarching purpose of this research programme was to measure mothers’ and birthing parents’ perceptions of, and satisfaction with, the maternity/perinatal services they had recently received through the surveys, and to compare their satisfaction with the results recorded in previous surveys (where possible). The objectives of the qualitative research with mothers and birthing parents known to be poorly served by the maternity and perinatal system, and with bereaved mothers and birthing parents, were to provide a deeper **understanding** of:

* What maternity and perinatal services look like when they are working well/not working well, including when cultural, identity and other needs are met/not met.
* The barriers and enablers to accessing services.
* The improvements in maternity and perinatal services these mothers and birthing parents would like to see in the future.

## Methodological overview

This qualitative research included a total of n=24 mothers and birthing parents from population groups known to be poorly served by the maternity and perinatal system (viz. Māori, Pasifika, LGBTQ+, young, and disabled mothers and birthing parents), who participated in mainly small group discussions, via Teams, between 31 August and 28 September 2022.

Research participants were either recruited through a networking approach or had identified that they would like to participate in further research, after participating in the cognitive testing for the 2022 Survey of Whānau/Families’ Experience of the Maternity System, or the survey itself. Participants were all fully informed about the research and had consented to take part prior to being interviewed.

Please refer to the appendices for additional methodological information, including a copy of the qualitative discussion guide.

## Report notes

The objective of the qualitative research was to provide **an understanding** of the experiences of mothers and parents known to be poorly served by the maternity and perinatal system, rather than to quantify these (which was the purpose of the 2022 Survey of Whānau/Families’ Experience of the Maternity System). Therefore, while it is possible to identify variations in responses, it is not possible to extrapolate these findings to all mothers and parents known to be poorly served by the maternity and perinatal system, or to specific groups of mothers and parents (e.g., young Māori mothers and birthing parents).

In addition to this technical report, additional reports have been prepared as follows:

1. A technical report based on the results of the 2022 Survey of Whānau/Families’ Experience of the Maternity System (Technical Report 1).
2. A technical report based on the results of the Survey and Qualitative Research with Whānau/Families Who Have Lost a Pēpē/Baby (Technical report 2).
3. A summary report based on all three technical reports.

# Midwife experiences

The following section discusses women’s and people’s experiences of finding a midwife. It also discusses their experiences of midwives throughout their maternity and perinatal journeys, including examples of both positive and negative experiences, and what sits behind these.

## Finding the right midwife

All but one of the mothers and birthing parents who participated in this research had an LMC, with most choosing a midwife. The one woman who did not have an LMC is relatively new to New Zealand, and the only maternity and perinatal support she received was from the doula whom she paid to assist with her home birth.

I didn’t know where to go… The only person of help was this woman from my husband’s work, and she linked me with a doula… I didn’t get the best support… I am just going to say that perhaps, because I am a person of colour, it was more difficult… Most of the time, I just don’t feel I’m going to get help or get anything… She was more of a birth doula… She did not offer post-birth support. (Disabled person)

The experiences of research participants in terms of finding a midwife varied.

Many mothers and birthing parents described their experiences of finding a community midwife as difficult and time consuming. As well as taking up to four weeks to find one, it also sometimes required searching outside of the ‘Find Your Midwife’ website (e.g., asking friends and family for recommendations, seeking assistance through Facebook groups).

Looking for a midwife on the site can be quite overwhelming because, when you look at dates for when you’re due, not a lot of midwives are available. (Pasifika under 25 years)

It took nearly a month to find a midwife. No one was available for the time of my birth. I had to ask one of my friends to recommend a lady she had as her midwife. I was comfortable with her, but I didn’t have a connection with her. (Pasifika under 25 years)

I couldn’t find a midwife off Find My Midwife because none were available in my area… I called all the ones who said they do home births… So, I had to post in a home birth [name of area] Facebook group asking, does anyone know if there is a midwife who will do a home birth in [name of town]? My midwife ended up messaging me through that page. (Disabled person)

Aware of the difficulties others were having finding a midwife, research participants who found theirs easily, often considered themselves lucky.

I was very lucky… When I found out I was pregnant, I called the midwives that had just moved into the same building as my GP. And they were just like, “Oh sure, can you come Monday?.” [I didn’t appreciate it at the time, but I now know] I was really lucky. (Pasifika 25+ years)

I was very lucky, as I was able to get in with the same midwife I had before. Because where I live, we were actually named the area in [name of city] with the most babies born in 2021. (Pasifika 25+ years)

By going through [sperm] donation, there weren’t surprises. We knew exactly when the conception date was, and so being able to jump in and get a midwife, basically the second a positive test comes through, makes a huge difference… I just went on findyourmidwife.co.nz, but I think, being able to get in early really helped with that. (LGBTQ+)

When searching for a midwife, mothers and birthing parents generally had some criteria in terms of what they were looking for (e.g., experience, home birth care, a midwife of the same culture or identity). Only a few found exactly what they were looking for.

I could just tell she was a real advocate and I just felt being tangata whenua or being a person of colour, you really need someone on your side in the system. This midwife, she was just so good, because she listened, and I felt really supported by her. (Māori disabled person)

I was looking for Māori and/or queer midwives and so I found the one queer-friendly midwife in my region and put in my enquiry and hoped for the best. (LGBTQ+)

She was Pākehā, and that kind of affected our connection. So, yeah, maybe if took time to look for somebody, I might go for someone that is a Pacific Islander next time. (Pasifika under 25 years)

Research participants who were unable to find whom they were looking for, either ended up settling for whomever they could get, or selected someone whom they thought would be the next best thing, given their criteria.

I think everyone was pregnant in [name of city] at the same time. By the time I got to the sixth name on the list, I was literally picking names out of the bag; this looks like a nice name. At first, I went off experience, and then, obviously, they’re not free. Then I went off location, and then I went off, I’m just going to pick anybody… It took me about 3-4 weeks until I found somebody that was actually free. (Pasifika 25+ years)

At first, I tried looking for a Māori midwife, but that was challenging in [name of city]. So, you just take the next midwife that says yes. (Māori 25+ years)

My first midwife was Indian. I thought I would be able to connect with her more on a cultural level. I couldn’t find a Māori midwife available at the time. In truth, she didn’t really dive too much into my cultural needs. (Māori 25+ years)

## Positive midwife experiences

Given the central role that midwives play in the lives of hapū/pregnant and birthing mothers and birthing parents, research participants had a lot to say about their experiences with their midwife.

Mothers and birthing parents who had positive experiences with their midwives, spoke very highly of them.

*I have the utmost respect for midwives because their job is not just to bring the baby into the world. The support that they have given to me personally is enormous. (Pasifika 25+ years)*

*We had a good bond – I had a great experience with my midwives. I can’t say enough about them. (Pasifika 25+ years)*

*Although my [second] midwife wasn’t as culturally and spiritually aware of my needs, she was amazing. She made me feel like I wasn’t alone. She would make a point of asking me if I was OK. Like, “I can see your baby is OK; we can stop talking about baby now. Are you OK? How are you feeling?.” (Māori 25+ years)*

A positive midwife relationship was defined in terms of having a ‘good connection’ and a high level of trust. Research participants who had positive relationships with their midwives described feeling cared for and supported. They also attributed this relationship with helping them to feel safe and empowered throughout their maternity and perinatal journeys.

The aspects of their midwife’s role that mothers and birthing parents valued, included the following:

* **Accessibility** – Making time for them. Never too busy to answer questions or put their mind at rest if they were feeling anxious or worried.

*I had a really good experience with my midwife. If I needed to know anything or wanted information, they would just give it… They were always available for me to call or text, if I was worried. (Pasifika 25+ years)*

*My midwife, she made it very clear that she was there for me when I needed her. (Disabled person)*

*When I was pregnant, if I needed anything, I could text her, even if it was 11 at night, and she would respond to me, to make sure I was alright. (Pasifika under 25 years)*

* **Educator** – ensuring that they were informed and, as such, well prepared at each stage of their maternity and perinatal journeys.

*My midwife drew the stages of birth, and I had that on my fridge… So, by the time the process started, I knew exactly what stage I was at. I just felt completely in control, and I felt super-informed. So, that [the birth of my baby] was a really beautiful experience. (Pasifika 25+ years)*

*My midwife was good at covering that you have just got your baby home, now here is what to expect [information]. (Long-term disability)*

*The information that I got from my midwife was pretty spot-on. You can only google so much, but if it comes from somebody that is actually experienced in the area, it makes a lot of sense. (Pasifika 25+ years)*

* **Translator** – making sure what was going on and being said was understood.

*Me and baby have different blood types. The doctor explained that some of my antibodies got into her bloodstream, so that was why she needed to go to NICU… I felt I understood what was going on far better through my midwife, than I did through the actual doctors. (Pasifika 25+ years)*

* **Guide** – ensuring they had a plan and the support they neededto navigate their way through any curveballs thrown at them.

*That week, she had been preparing me for what was coming, even down to where I would park my car. So, I knew exactly what was going to happen… prepared me that I would be discharged before my baby… It would have been a far worse experience if I wasn’t given the heads-up… She prepared me for that and then supported me through that. (Pasifika 25+ years)*

* **Affirming** – ensuring they were doing well and/or doing the right thing.

*I was pretty anxious about my age and my weight and all the extra risk factors and, when I bought that up at my first appointment, my midwife was just like, “Why is this an issue? Every pregnancy is different, and everybody is different and if there ends up being issues, we will deal with them.” They just made me feel really confident. That’s how everyone deserves to start their pregnancy. She just made me realise, oh yeah, my body is just fine how it is… (Pasifika 25+ years)*

*I felt safe to be queer with my midwife. I felt safe knowing that my midwife wasn’t judging us on our whānau structure… My midwife was actively supportive, but I think, even having one who is neutral on it would be better than having someone who made me feel like I was an outlier and doing the wrong thing by have a planned life that doesn’t fit the heteronormative patriarchal thing. (LGBTQ+)*

* **Advocate** – standing up and going the extra mile for mothers and birthing parents, when needed.

 *My experience in the hospital was quite unique, because I went in with my midwife and then she was the only person I interacted with until after the baby was born… She met my needs amazingly in the hospital. She was incredible… She made this incredible sort of bubble around us. I guess, she knew that I was coming into hospital wanting a home birth, so she kept that for me. She met my needs fully. (Disabled person)*

*I felt like my midwives had my back. I was confident they understood what I wanted. (Pasifika 25+ years)*

*The specialist at the hospital sends you a letter every time after they have seen you, and the letter says, ‘Dear [name] and then it says, problem list, like overweight BMI ...’ That is important for them because my pregnancy is high-risk, but I don’t think it is a very good way to interact with the patient, starting the letter with a problem list. My midwife also thought this was inappropriate. And the letter people took away the problem list because my midwife advocated for me. (Disabled person)*

* **Life buoy –** providing calmness and confidence in a crisis.

*I wasn’t really expecting to go through an emergency C-Section again, so that was kind of a shock to my system… But my midwife was so calm. She even came with me right ‘till I went to theatre. She didn’t have to, but she did. So, that kind of gave me confidence. (Pasifika 25+ years)*

*She was calm, so I didn’t worry… She just kept me real calm. (Pasifika 25+ years)*

## Negative midwife experiences

While some mothers and birthing parents were happy to be cared for by a team of midwives, other research participants were adamant that this didn’t or wouldn’t work for them, largely because of their experience of, or perception, that there would be communication issues.

*[If I could have changed anything], I would have probably changed midwives because my midwives were working in a team and so, I didn’t really get to develop a relationship with any of them and, if I called one of them and told them about a problem, it wasn’t communicated. Then, the next time I would call about the same problem, it would be a different person… [it] made it hard to be able to talk to them about what was going on. And hard for them to know the situation. (Māori under 25 years)*

*In our antenatal class of maybe 15 couples, we were maybe one of two that actually had a midwife. Everyone else had to go through the team at the hospital, which I feel would have been exhausting. I feel really lucky that we [only] had one person to explain the way our family works… Having my one central midwife for most of my care was really crucial. So, I only had to explain things the one time and then it wasn’t a problem. When I started getting the revolving door of midwives in the hospital is when issues started, and you had to keep on explaining. (LGBTQ+)*

**Poor connection with their midwife**

Those who were the least satisfied with their midwife were those who experienced little, or no, connection with their midwife, largely because they felt their midwife was generally too busy and disinterested in meeting their needs.

*I felt like the midwives didn’t really listen to my concerns. I was quite unhappy in my pregnancy, and I don’t feel like they really took that seriously… You could see she was really busy. Everything was rushed. The way she would talk would just be straight to the point. There wasn’t a lot of connection, I suppose. It was just what you need to know, bad or good, and then kind of move on out the door. (Māori under 25 years)*

*She only gave me pamphlets to read and books, she didn’t really talk to me much. I didn’t really have appointments with her either. She would see me once a month or once every two months… I felt like the sessions were cut short, just because she had a lot of clients. (Pasifika under 25 years)*

*So, I was in NICU for 3.5 weeks, as I had my boys five weeks early… My midwife kind of stepped away… I think I saw her, maybe twice… I probably expected a bit more from her. Just to get to know her some more and her to know my babies, so that, when we went home, it didn’t feel like different. When I got home, I didn’t have one visit and I thought I would, because I had two babies. (Māori 25+ years)*

**Issues around information – lack of it**

Issues around information sharing was another source of dissatisfaction with midwives. Some, especially first-time mothers, and birthing parents, felt that their midwife hadn’t provided them with all the information they needed to be prepared for the various stages of their maternity and perinatal journey. For example, information about what to do if pēpē/baby wasn’t moving (much), about giving birth and the realities of life after birth.

*I wish I had known prior how serious it is if baby is not moving. (Māori under 25 years)*

*More information about the birth would have been helpful. Maybe even have a birth simulation, so that you are prepared for episiotomies and things. (Pasifika under 25 years)*

*All I wanted was to know what happens after birth. Like, I didn’t realise that a baby is going to be up most of the night with cluster feeding. And probably, more, like the baby blues and stuff. I didn’t realise that everything changes, pretty much. (Māori under 25 years)*

Information needs included being better prepared for the potential stress, and sometimes shock, associated with having to make changes to their birthing plans, as well the possibility that their midwife might not be present at their pēpē/baby’s birth, if they needed urgent medical intervention or surgery, or postnatally (if the hospital had taken over their postnatal care).

*She didn’t give me much information. I thought my birth would be easy and chill, but my birth was different. She didn’t tell me how hard it was going to be, or what it was going to be like being around people when you were giving birth. It wasn’t nice… She didn’t tell me how I was going to feel because it was my first time. (Pasifika under 25 years)*

*My most important thing was, if the birth plan didn’t go to plan, what were the alternatives? (Māori under 25 years)*

*More information on what they [midwives] are able to do and provide for you in case the shit hits the fan. Like, when I got my epidural, my midwife pretty much left the hospital. I didn’t see her again. So, I think if she had explained that to me prior to the hospital, I would have been a lot more prepared and not so shocked… To touch on what others said about midwives not being at the birth and not showing up much after the birth. I also had a similar experience but, then I found out if midwives aren’t epidural certified, they have to hand your care over to the hospital and leave the grounds. I was unaware of that with my big girl, so I was kind of like, where are you going? She just handed me over to complete strangers and then back-up midwives came for the after-care home visits, and I didn’t see my midwife after that. She was gone. (Māori 25+ years)*

Disabled mothers and birthing parents reported that their midwife’s focus on the potential problems associated with their pregnancies and birth plans left them feeling anxious and scared.

*I made an appointment to see the midwife, and my husband and I went to meet her. She said, “You are very high-risk because of your disability.” Also, I have a mental health issue. So, I just don’t think you should say it to people in those words… It kind of scared me that she seemed scared. So, how am I meant to put my trust in her, if she is scared, because she is meant to be the professional. (Disabled person)*

*I’m sure she didn’t mean to, but it felt like scare-tactics. Like, very unnecessary extreme situations that could happen, and that made me uneasy… It was scary and I left one of the appointments very anxious; quite panicked. It was just too much, and it wasn’t presented in a very helpful way… It got to a point where I had to tell her, “This isn’t working for me. The things you are telling me are just not helping.” (Disabled person)*

**Unprofessional behaviour**

The only other criticism research participants made about their midwives related to what they considered to be unprofessional behaviour.

One research participant reported having a midwife who was disrespectful and overly familiar in the way that she talked to her.

*My husband was supposed to touch my child first… But I felt like she [the midwife] got too comfortable with me because [of] the things she would say. She was like, “OK, but actually, I’m going to touch her first, because I’m the one that is examining you,” and she’d laugh it off. And I’m not actually laughing. I’m serious, because through the antenatal classes, I was told by the lady, you can actually advocate for how you want your birth, and you can tell your LMC. So, I was a bit taken aback by it… I told my midwife, “Are you going to check [my stitches]?” and she said, “Oh no, everything down there should be fine. If it’s crooked, it’s your fault”. I think she felt we were too comfortable because my baby got heat rash and she was like, “Oh, your baby is ugly now” …and I was like, what the hell? You are in my house, in my bedroom and it’s only you and me and you are saying that to me? …I’m not a confrontational person. I just kind of felt bad, like is she doing this to other mothers who are kind of like me? Because if it was anyone else, she wouldn’t have done that. (Pasifika under 25 years)*

Two research respondents reported feeling pressured by their midwives to do things they didn’t want to do; one to have a COVID shot and the other to breastfeed.

*At the time that everyone was getting encouraged to get a COVID shot, it was discussed more than anything in our midwife appointments. So, I felt like even though I was going to get it, I had to get it. (Māori 25+ years)*

*When I got home, my midwife was really pressuring me. Kind of like, breast is best, which I understand but, when you’re a new single mum, I just felt like formula was a good option because he was slowly losing weight. She just kind of made me feel a failure for wanting an alternative. So, we had to snip baby’s tongue tie and I just mix-fed him in the end. (Māori under 25 years)*

# Antenatal services

## Access to antenatal classes and Hapū Wānanga

This research identified several enablers and barriers to accessing childbirth education and antenatal classes and wānanga. These included those relating to finding wānanga and classes and their perceived value from a learning perspective.

#### Timing and location

Times that did not suit and difficulty getting there, if not online, were barriers to finding and attending classes, especially during the early stages of the COVID-19 pandemic and during COVID-19 lockdowns.

*I had no antenatal classes or anything because, when we went into lockdown, that was the last three months that I was pregnant, and I didn’t think I would have been able to make the classes with work and just finding classes in West Auckland at the right time and everything. (Pasifika under 25 years)*

*Just because of COVID, I guess. That’s why all the classes [that] I was interested in weren’t available at the time… It would have been beneficial to learn how to relax during contractions and how my husband could advocate for me… We weren’t prepared as first-time parents. (Pasifika under 25 years)*

In contrast, being able to find wānanga or classes at times and locations that were convenient, especially being able to fit these around work, enabled access.

*Hapū Wānanga was a three-day course during the week and my partner couldn’t get time off work. The other one [Young Mum’s antenatal class] suited our schedule better. (Māori under 25 years)*

*I was so busy working when I was pregnant, I found easier doing the one antenatal class a week and just a dedicated two hours. That was really handy for me. (Māori under 25 years)*

#### Not being well advertised

Some Māori mothers and birthing parents would have liked to have attended Hapū Wānanga, but they had either not heard of any in their local area and/or they believed they were not eligible to attend. For example, because they were not local iwi and/or they did not attend the whānau-centred services offering these.

*The Māori culture in [name of city] is quite big, so I don’t know why they don’t have the same things available. (Māori 25+ years)*

*I know a lot of services [names of two whānau-centred services] that offer [Hapū Wānanga] classes, but I didn’t get to have those chances because, 1) I’m not under them as a patient and 2) I’m not from this area. So, it’s a case of who you know. (Māori 25+ years)*

*So, the dumb thing about [name of local iwi] is, it’s who you know, who you have connections to… I’m listening to your guys kōrero and it’s like, oh no, you didn’t get to go [to Hapū Wānanga]. [Name of Kaupapa Māori healthcare service] push a lot of their stuff, but they don’t really go to the DHB or the other mainstream clinics or anything. They have a lot of wānanga; day wānanga and Hapū Wānanga and they’re amazing. (Māori 25+ years)*

A research participant from a small South Island town also identified poor advertising as resulting in the low turnout of what they described as an excellent workshop.

*It [Plunket antenatal workshop] was a great experience and helpful for most things... They put so much information into the workshop that lasted for two days, like breastfeeding, parenting styles, information about labour and also the risks and benefits that I wanted to know about… I found out about it from a family member who had seen a post on Facebook. It wasn’t advertised anywhere in town or in community groups or anywhere that people would see it. So, it had really poor turnout. (Disabled person)*

#### Fit, in terms of classmates and how the course was run

Classes that were not a good fit for some mothers and birthing parents who participated in this research (e.g., because of who they were targeted at) were poorly attended and the information presented was less likely to be absorbed, because of their discomfort of being there.

*Because I was young, I didn’t really know much information. I did attend one [antenatal] class, but I felt real young and the other parents were quite… I felt a bit awkward going to them… It was just an age thing. (Māori under 25 years)*

*So, I found with the class that we did in person that my ability to take stuff in was quite impeded by how weird I felt about being there… Things like sending the dads out of the room and me having to stand there awkwardly with a whole bunch of guys who were [thinking] like, ‘what the fuck are you doing here?’, kind of thing… So, I guess, if that was my only exposure to antenatal education, it wouldn’t have been very successful. And that’s from an antenatal instructor who I think was trying really hard… It makes it difficult to take in information when you have got that other stuff on top. (LGBTQ+)*

*The person running ours put a lot of effort in, which I appreciated. But it also meant that they were coming up to me during every single break to check in and make sure that they did it right. So, it was kind of dammed if you do and dammed if you don’t. I could have sat there and been misgendered or I have to sit there and hold their hand and reinforce, “Yes, you’re doing a good job”. I just wanted to be there to learn things. (LGBTQ+)*

On the other hand, well run wānanga and antenatal classes that were targeted at specific community groups (e.g., young mothers and birthing parents, Māori, Pasifika, LGBTQ+), were much more likely to be enjoyed and valued by those who attended them.

*When I had my [first] son in Auckland, I went to a day wānanga at a local marae. I went with a whole bunch of other hapū māmā and we made our own wahakura together and then we were given a whole lot of information pertaining to te ao Māori for our babies, like muka clips and different ways that they practiced birth back in the day… It was amazing. (Māori 25+ years)*

*We did an online one [antenatal class] with [name] and that was a really nice counterbalance to the bullshit we were getting in the other class… It was like a breath of fresh air… It felt like we could relax and talk about the things that we wanted to talk about, without this other filter on top of it… I think that general lack of assumptions was really helpful… There was no normal that we weren’t a part of. There was no normal, it was just… anyway you want it… We learned things that we didn’t even know were an option from these other antenatal classes… I think the real key message I took from that course, aside from the useful stuff we learned about childbirth and things, is the way that we were going to give birth and parent was right because it was right for us. (LGBTQ+)*

## Access to scans

This research identified several barriers to accessing ultrasound scans during pregnancy. Cost and trying to find a subsidised provider, were the greatest of these.

#### Cost

The costs associated with scans was regarded as a significant expense for some mothers and birthing parents who participated in this research, especially if they were unable to access subsidised scans, or had been required to have additional scans.

*Scans were so expensive. I think my growth scan was like $180, or something. (Pasifika under 25 years)*

*I ended up doing four growth scans and those were $50 each. So, there is a cost involved. (Māori 25+ years)*

#### Confusion about which providers were subsidised

The burden of cost was reduced for those research participants who had been advised by their midwives where to go for subsided scans.

*I didn’t mind the scans because my midwife told me where to go that was cheap for me. (Māori under 25 years)*

Those who weren’t informed had both the extra expense and frustration of trying to figure out which providers were subsidised on their own.

*You go to one place and it’s cheaper and then you go to somebody else and you’re paying double the price. (Pasifika under 25 years)*

*My midwife didn’t tell me that some places cost and some places don’t. So, [name] was free and [name] was $50, and they don’t tell you. You kind of have to figure it out for yourself. (Māori under 25 years)*

*One thing I did find hard was understanding how scans work. Like, getting the referrals from your midwife and going in, and then some places you don’t have to pay and then sometimes its $100. (Māori under 25 years)*

#### The ripple effect of limited appointment options with subsidised providers

Limited appointment options, especially with subsidised providers, meant scans were often overdue, as it was not unusual for some mothers and birthing parents who participated in this research to have to wait three to four weeks for an appointment. For some, there was the added requirement of needing to travel long distances.

*You want to find places that have the subsidy, where you only pay half price, but they’re fully booked. Then there was only an appointment at 10am or 11am, or you would be waiting for almost a month. I even had to travel over to the North Shore to get my first dating scan. And I was only able to have my growth scan right at the end when I was pregnant because they didn’t have anything available. (Pasifika under25 years)*

*Like, it was very hard to find an appointment… Like, you need to get your 36-week scan, but you can’t get it for three weeks. And because I am on rostered shifts, it was difficult for me to actually find a time that was available. (Pasifika under 25 years)*

*There were no long times for scans. So, I didn’t get my 20-week scan until 23-weeks. (Māori under 25 years)*

#### Scan booking process variations between providers

Lack of awareness of the variations in the requirements of different providers, in terms of their booking processes, added yet another barrier to getting a scan for some research participants. For example, some providers required a referral to be sent through before booking an appointment, whereas others were happy for mothers and birthing parents to make an appointment and to bring their referral with them.

*Some places for scanning, you can’t actually book an appointment until they have seen your referral. That can be hōhā sometimes. Just because of the excitement of going for a scan, and you want to ring and book them straightaway and then to be told, “Oh, we need to see your referral first.” It would have been nice for the midwives to point that out. But other places just take your appointment in and it’s sweet. I have learnt now. (Māori under 25 years)*

#### COVID-19-related restrictions

Not being able to bring anyone to scans during periods when COVID-19 restrictions were in place made it difficult for those research participants with children and was stressful for those who felt they needed a support person present.

*With the COVID restrictions, going into scans you couldn’t take your partner, which was quite sad. (Māori under 25 years)*

*With COVID, the one support person when it came to scans was quite emotional and hard to handle on my own, especially as I had a lot of growth scans, and I had a few complications. (Māori 25+ years)*

*I would have to wait for my husband to get home and watch the kids because I couldn’t take just one or two kids. (Māori under 25 years)*

#### The impact of caring versus uncaring interactions with providers

While not necessarily a barrier to having future scans, how mothers and birthing parents were treated during the scan process impacted on their feelings about the experience. For example, some mothers and birthing parents reported that interactions with sonographers whom they perceived as uncaring or insensitive, left them feeling uncomfortable or upset.

*I know the scan places aren’t with the maternity health system, but some of the scan people, especially my first dating scan, they can come across as quite rude. That’s the only bad experience I had when I was pregnant. When I went for my first scan, I had to have an internal scan and that was ok, but she couldn’t see anything, and so she basically said to me, “You have either miscarried or you’re too early”. And I was like, “OK, so I might not have a baby?.” (Pasifika under 25 years)*

On the other hand, genuinely warm and friendly interactions left them feeling good about the experience.

*So, when you have a disability, you get extra scans. The scan team were amazing. I think it was because I got to say kia ora to everyone, and they were like, “So, what iwi are you from?” …I couldn’t believe it because I have had so many experiences with racism. (Māori disabled person)*

## Outpatient specialist care experiences

Mothers and birthing parents who had health or pregnancy-related complications, for which they required outpatient specialist care prior to the birth of their pēpē/babies, reported both positive and negative experiences.

### Positive experiences

Two research participants who had diabetes were both impressed by how quickly they were seen by specialist diabetes teams.

*I was really impressed with the process… Once I was diagnosed, it happened really fast… I had a test on Wednesday and had the results by that evening and the call with the midwife. By Friday, I was seeing the diabetes midwives and specialists to go through everything, and I think I had a call with the nutritionist on the Monday or Tuesday. (Pasifika 25+ years)*

*I live with type 2 diabetes... As soon as I found out I was hapū, I went to my GP, and she straightaway referred me to the specialist diabetes team at [name] hospital… I actually saw them that week, because I was already five weeks pregnant and because of my GP pushing… So, I got in that week and it’s really hard to get in, because the whole system, as you know, is all backed up. So, that part of the journey was really good for me. (Disabled person)*

One of these specialist teams minimised the negative impact of the requirement to attend additional appointments and scans, by scheduling appointments on the woman’s behalf and co-ordinating these, so that she saved time by seeing all the people she needed to, one after another.

*I had a lot of extra monitoring for the diabetes, but I didn’t have a problem accessing it. I don’t know if this is unique to [name of DHB], but they would schedule all my appointments back-to-back. So, I could go and have a scan, the scan would go straight to the obstetrician, and I would see the diabetes midwives. I would see everybody all in a row and it was done. It was amazing. And then the person at the desk would be like, “OK, we will mail you when your next appointment is.” (Pasifika 25+ years)*

### Negative experiences

On the negative side of the ledger, a woman suffering from mental health issues during their pregnancy reported being unable to get the support they needed.

*Earlier in the pregnancy I got really bad anxiety and I have a history of anxiety, so it wasn’t out of the blue. I also have a really long history, and am now in recovery, of eating disorders. So, these two things sort of popped up in pregnancy and postpartum, as well. I tried so hard to get support and there just seemed like there was none. (Disabled person)*

A woman with a long-term disability was also unhappy at not being given the opportunity to have an active role in her birth plan.

*Because of my disability, I had to be induced… So, when they presented like, that’s the plan, you’re going to be induced… they had already decided in their meeting of which I was not a part of, which was a concern for me, because it is my body and my baby. (Disabled person)*

Other concerns reported by those requiring specialist services included the apparent lack of co-ordination between the medical professionals involved in their care and being made to wait for long periods (sometimes hours), despite having scheduled appointments.

*What I found was that the information that the professionals give, like the diabetes [specialist] gives us; the midwife gives us; the doctor gives us, they are all focused on their own part of the labour and birth. It is not holistic. (Disabled person)*

*Because I was carrying twins, I had a lot of specialist appointments. I was kind of handed around a lot. I felt like every time I went in, I saw a different person. It was really unsettling because it was hard to know what was happening. (Māori 25+ years)*

*When you go to the appointment for the diabetes, you kind of have to wait for an hour and a half, 2-3 hours sometimes. I’m just wondering if they could have a better system, like texting when it’s closer to the time, because the hospital is not too far for people to get to. And then you could go, instead of all waiting there, especially with COVID and if you have tamariki. (Disabled person)*

# Hospital experiences

This section of the report describes women’s and people’s experiences of the hospital, before, during, and following the birth of their pēpē/baby.

## Positive experiences

As discussed earlier (see section 3.2), some mothers and birthing parents who participated in this research reported very positive experiences in relation to their midwife’s involvement in the births of their pēpē/babies.

Some of the mothers and birthing parents who had extended hospital stays (e.g., because of pregnancy complications or because their pēpē/baby needed extra care), also reported very positive experiences.

*Everyone in the hospital was really lovely and amazing and I was really well looked after, especially in the neonatal unit. (Māori 25+ years)*

*I was in hospital for one night because baby needed to be resuscitated a bit… [the] hospital staff were amazing. (Māori 25+ years)*

*The nurses at NICU for my second born were amazing. (Māori under 25 years)*

## Negative experiences

Women’s and people’s less than satisfactory experiences of the hospital are discussed under the following headings: feeling frightened and vulnerable; feeling unwelcome; not being listened to and feeling pressured; unmet needs (including physical, cultural, and identity).

### Feeling frightened and vulnerable

Factors that were reported by research participants as resulting in them feeling frightened and vulnerable when in the hospital environment include those related to culture and identity, as well as situation-related factors.

#### Cultural and identity related factors

Some mothers and birthing parents described the prospect of a hospital birth as nothing short of terrifying.

Two Māori research participants identified their distrust of ‘the system’ and concerns that they might not get the same level of care as others because of racism, as underpinning their fear and vulnerability.

*I was terrified throughout my pregnancy, and I still am now about Oranga Tamariki taking my baby away from me because I am Māori. I have seen uplifts happen before, so I have a lot of mistrust in the system. Even going to the doctor with my baby because he is just a little guy, I was worried that they would think I’m not feeding him, so I called La Leche League, the breastfeeding people, and had them back me up, and I was making sure that my doctor was writing that in her notes. (Māori disabled person)*

*I did see it while I was there [in hospital], the ladies who looked Māori, it’s like they felt like they didn’t have a voice. They would just back-down and not speak-up and that’s really sad. (Māori under 25 years)*

For the LGBTQ+ mothers and birthing parents who participated in this study, being in (or anticipating being in) hospital was associated with feeling vulnerable, unsafe, and needing to *“armour-up”* to protect themselves. As a result of these feelings, some LGBTQ+ mothers and birthing parents participating in this research stated a definitive preference to give birth at home or in a birthing unit and, if a hospital birth was unavoidable, to minimise their stay. One birthing parent blamed their negative hospital experiences for the bad start they and their partner had as parents.

*I would say I am planning for a home birth and people would go, “Oh well, you’re so brave.” My internal response was that this is not about bravery or strength. I’m not brave enough to plan on a hospital birth. Like everything about that feels absolutely terrifying to me. (LGBTQ+)*

*We ended up needing hospital care, but our preference was definitely to be in our home or… in a birthing unit, instead of the hospital. I think, on reflection, that was about trying to protect ourselves… Wanting to cocoon in our own way, without a lot of medical interference and people that we would have to educate and talk to. On reflection, I think we left hospital earlier than we could have… but I just wanted to get back to our safe little bubble, where we didn’t feel so vulnerable. (LGBTQ+)*

*When I ended up having to have a caesarean … the surgeon decided it was a great time to argue with me about whether they/them pronouns were a valid way to identify… there was so much stress and then, also feeling like this person is about to have both mine and my kid’s life in their hands and I don’t know how much I can push back… You don’t want to deal with that kind of power dynamic. It’s calling into question if something goes wrong, did they maybe not do things quite to the level that you would expect because there is some sort of implicit bias going on? It made a really stressful situation 10-times worse. (LGBTQ+)*

*When we did finally get out of the hospital and were able to come home and put that armour down, you start dealing with the impact of having been in this really non-inclusive, gendered, heteronormative space. This time, that should be really joyful and really happy, having just brought home your kid, for me and my partner was really traumatic… The first six months or so of having our son at home was also really difficult mental health-wise, and both of us ended up needing to go and seek out professional help. (LGBTQ+)*

#### Situation-specific factors

Some mothers and birthing parents described feeling fearful and vulnerable, because of the situations they experienced while in hospital. These included:

* **Being left alone for long periods of time.**

Examples included, when arriving at hospital to give birth and while waiting for their midwife.

*When we got to the hospital, because we were in lockdown and because they were understaffed or something, it was really hard. The lady showed us our room and then she disappeared and never came back. I pretty much put myself on the bed and everything because I was waiting for the midwife to come. The hospital midwife never came back to check me, but I think she needed to, because when my midwife arrived and checked me, I was already 10cm and ready to push. If my midwife was late, nobody would have been there, and I would have just had that baby on my own. (Pasifika under 25 years)*

*I went for a normal growth scan and then, two hours later, I had four doctors in the room telling me that I was going to have my babies in an hour… I felt really unprepared and had a lot of anxiety. My husband wasn’t there, and my midwife wasn’t there. It was just nuts… They left me in the room for about four hours wondering what was happening and then said, “You’re going to have a steroid injection now to increase the babies’ lungs and you need to be back here by 12pm tomorrow because you are going to have these babies”. It all happened very fast, and it probably wasn’t the best way to go about it because, later on, I found out there was nothing medically wrong with the babies. The only thing was a little bit of growth. (Māori 25+ years)*

* **Worrying that no one was going to care for their pēpē/baby.**

Examples included, when returning to hospital with their pēpē/baby for surgery to remove retained product, and not feeling physically able to care for pēpē/baby because of the effects of an epidural.

*I had to go back into hospital because I had retained product. My husband couldn’t come, which was quite scary… There was no one to watch over the new-born, so that was quite hard. I was thinking, is the new-born going to be in their bed while I have surgery? I was so worried about it… I was crying so much, they allowed him to come up. (Māori under 25 years)*

*After I had my surgery, I had an epidural... They were not going to let my husband stay. I couldn’t even move to attend to my baby, so I was just bawling my eyes out… I felt like I was crying for a long time. They finally said that they would put me in a private room and that my partner could stay… I didn’t understand how they expected me to look after my baby. (Māori under 25 years)*

* **Not being adequately prepared for the birth.**

Examples included, not knowing that back pain was contractions, and not understanding how preeclampsia would affect the birth.

*To be honest, I wasn’t really told much about the induction. I didn’t really know you could get back contractions because that is what I had. I had only seen people have tummy contractions… So, when they like told me, “A contraction is coming,” like, I had no idea. I just felt a shooting pain along my back, but I didn’t know that was contractions, until my hairdresser was telling me about all her births, four months later. (Pasifika under 25 years)*

*I was induced with my daughter because preeclampsia can be classified as quite dangerous to the baby and the mum. I wasn’t aware of what was happening, and I was quite scared… I just wished they had educated me a bit more about what was going into my body. I didn’t properly meet my daughter until 24 hours after she was born because I had to stay on all this medication, but I didn’t understand why, and I still don’t understand why. (Māori 25+ years)*

### Feeling unwelcome

Some mothers and birthing parents felt unwelcome in the hospital environment. The reasons for feeling unwelcome included:

* **Not feeling they fitted-in or belonged.**

LGBTQ+ mothers and birthing parents participating in this research described feeling like they didn’t fit-in or belong in the hospital environment.

*Just always feeling like the outsider. Like we are the token couple at the antenatal class and the queer ones on the ward. Like, no one ever assumes that a couple is not a man and a woman. That’s just like the default, so anything other than that is something interesting or something different. So, you never feel relaxed because you feel like you are being looked at. (LGBTQ+)*

* **Staff perceived as uncaring.**

Experiences of hospital staff who were perceived as uncaring left some research participants feeling unwelcome and not wanting to stay for longer than was absolutely necessary.

*I had to ask myself and knock on the door of NICU and ask to be shown around to where my babies would be. No one actually talked to me about that. I knew I was going to have surgery the next day, so I asked and got treated not very nice. (Māori 25+ years)*

*They weren’t very nice. They told me I wasn’t allowed to be discharged from the birthing area until I peed… When I finally peed, I had to ring the bell, but when I rang the bell, the lady came in and she goes, “If you want help, you don’t ring the bell around 3pm, because we are in a huddle”. I said, “But yous told me to,” and she said, “Well, we are busy, and we can’t answer.” (Pasifika 25+ years)*

* **Feeling pressured to leave hospital.**

Some mothers and birthing parents who participated in this research felt pressured to leave the hospital after the birth of their pēpē/babies, before they were ready. This included a woman whose pēpē/baby still needed care and she didn’t have alternative accommodation.

*After giving birth to my baby, because he was in NICU, they wanted me to find accommodation. I couldn’t because I had nothing. I had no possessions with me because I had just come from [name of town] … I kept trying to explain, “I have got nowhere to go, can you just wait?”, and she was like, “Oh, we need the room for the mothers who had a C-Section”, which I understood, but I just felt like it was an in-and-out process, and I hated it. (Māori under 25 years)*

*Treated like crap; like I wasn’t important. I didn’t feel like they really cared. They just wanted me out, so they had a free bed. (Pasifika 25+ years)*

*It was about eight hours after having my daughter and they were trying to quickly push me out… I was like, “I have only just had her, can I please stay at least one night, to make sure that everything is OK?.” They were, “When do you want to go home, because you’re fine?” …I ended up back in hospital a week later with blood clots in my pelvis and one wrapped around my ovaries. It was hectic. I was there for ten days because they couldn’t figure it out. (Pasifika 25+ years)*

### Not being listened to and feeling pressured

Some younger research participants described feeling as though they were not listened to and were pressured into doing things they did not want to do, while in hospital (e.g., to breastfeed their pēpē/baby, start birth control, have a COVID shot).

*I gave birth at the birthing unit. I felt pressured into breastfeeding. And I feel they could have been a bit more patient and there could have been other ways for them to teach me; just being my first baby. (Māori under 25 years)*

*After I gave birth in the hospital, I had a doctor come and talk to me about birth control. I felt like she was really pressuring me. Like, she even said that she didn’t want me to leave the hospital until I had given her an idea of what birth control I’m going on… I felt really upset. I felt like she was picking on me because I was a young mum. (Māori under 25 years)*

*When I went to the maternity unit, there was a midwife who was very opinionated, and she was asking me if I was vaccinated. I said, “No,” and she pretty much put my name down for a vaccination the next day. And then I said, “Oh, my husband is coming tomorrow,” and she was like, “Oh yeah, I will put his name down too.” I hadn’t even made my decision yet and she pretty much forced that on me. (Pasifika under 25 years)*

While she got her way in the end, through the advocacy of her midwife, a sexual abuse victim who only wanted her vulva and vagina touched by her midwife, was repeatedly told by her doctor that she couldn’t have her wish.

*Because of my trauma, I only wanted my vulva and my vagina being touched by my midwife, but, of course, she doesn’t get paid for that and the doctor told me, “No, she can’t come in”. She came in because she is an advocate… She came in and did the examination for me. But the doctors had originally told me “No.” All their communication was “No.” (Disabled person)*

### Unmet needs

Some research participants reported having had better hospital experiences when they birthed their older children, because they believed that in the past hospital staff were focused on meeting both their **and** their pēpē/baby’s needs. In contrast, their experiences during their most recent births left them feeling that hospital staff were focused on meeting pēpē/baby’s needs and were less interested in, or were unable, to meet their needs (e.g., because of staff shortages).

*Thinking back to when I had my other two children, it was us as a unit. It was māmā and baby’s needs. I felt, with my recent baby, it was all about what’s best for baby. Baby this, baby that, which is great because, obviously I want a healthy baby, but I was hardly ever asked as a mum. (Māori 25+ years)*

 *I think, their main focus is just to get the baby out safe, and I think, everything else for them just goes out the window. (Māori 25+ years)*

#### Unmet physical needs

Research participants were generally of the opinion that the physical needs of mothers and birthing parents and especially their pēpē/babies were prioritised over other needs (e.g., cultural, identity) by the hospital system and that these were generally met.

*I found the hospital system focuses on the physical. That is their main priority. (Disabled person)*

Examples of complaints, in relation to physical needs not being met, included not being cleaned up after birth, dirty towels and sheets being left in their room and concerns about the suitability of the hospital food for a diabetic.

*While I was at the hospital, no one cleaned me up after giving birth. So, I was sitting overnight in my own blood with big clots coming out. (Māori under 25 years)*

*This time around, I feel like they had dropped the ball big time… I was bleeding and I asked for a clean sheet, and they said, “Oh yeah, it’s coming,” and it never came. So, I literally took it off and chucked it in the corner. It stayed there for three days next to me, including the towels that I had used. (Pasifika 25+ years)*

*My biggest thing, when I first got to the hospital for my induction, was the food… I’m not going to say it was bad, but I had diabetes and, basically, the food was like egg sandwiches on white bread with mashed potatoes and vanilla custard… All things that, if I ate it, would have spiked my blood sugar. And, since I was about to have my baby, if I was spiking my blood sugar right before he was born, he would have trouble regulating his own blood sugar and that could have led to more health issues. (Pasifika 25+ years)*

#### Unmet cultural needs

#### *Whānau Māori*

For those Māori māmā and people who identified their tikanga Māori needs as being important, meeting the cultural and spiritual needs of their hapūtanga journeys was just as important as meeting their physical needs.

*Anyone’s cultural needs are just as important as COVID awareness and immunisation shots and all those other things that they talk about and teach us. I think it should be just as common practice to bring up what is important to us [culturally]. (Māori 25+ years)*

*From our background, our whānau would take our placenta home and we bury it with the ones we have lost recently, and they look after the pēpē during their lifetime... So, that is why it’s really important to us as Māori, because they have kaitiaki guarding them throughout their life… And I really wanted the muka tie because that wasn’t around when I had my other two children and I thought, what amazing cultural thing to bring in with the harakeke. (Māori 25+ years)*

While some Māori māmā and people were satisfied that their cultural needs were met while in hospital, others, especially those who had planned for a home birth, were disappointed.

*Some of us can’t have home births, because of certain situations. So, we have to have home births at the hospital. So, if a muka tie is the way that we can make that certain experience the only cultural connection we have, then it has to be important. You can’t just forget about it… And, because the reality is, we aren’t giving birth the way our tūpuna did back in the day and so, any way that we can contribute to our culture and who we are into our birthing stories and our hapūtanga journeys is always important. (Māori 25+ years)*

*I think, as soon as you walk into the hospital, your true cultural needs are already gone out of the window. I think, for most of us, it’s just unavoidable, unless you have a home birth, and you want it that way. The hospital does take over and it is what it is. (Māori 25+ years)*

Examples of the way in which cultural and spiritual needs were not met included:

* **Cultural and spiritual needs not being asked about or discussed.**

Most research participants, including Māori māmā and people, reported they were never asked by their midwives or hospital staff about their cultural or spiritual needs. If these were discussed, it was at their initiation.

*I was never asked, “What are your cultural and spiritual needs?.” It was just all about what’s best for the babies. (Māori 25+ years)*

*We live in New Zealand. Saying kia ora in the hospital is a basic thing that people can do, but they don’t. They did allow us to tie his placenta with a muka tie, so, culturally, that’s good. But there is still so much work to be done… They didn’t ask me if I wanted a karakia, so that’s a Māori prayer, it’s not religious, it’s about the energy in the space… I reckon it should be part of their processes in caesarean sections. (Māori disabled person)*

*Cultural needs were never really discussed… And then the spiritual needs, again, were just never mentioned. (Māori 25+ years)*

* **Cultural and spiritual needs were assumed.**

Some mothers and birthing parents who participated in this research reported that hospital staff made assumptions about their cultural needs, based on physical appearance.

*I definitely don’t look Māori. So, depending on who the doctor is, I do get treated differently. Like, my midwives didn’t expect me to ask for a muka tie and for my placenta to take home. I had to advocate that for myself. Maybe, if I was a bit darker, they might have suggested it to me. (Māori under 25 years)*

* **Requests to meet cultural and spiritual needs may have been agreed to, but not followed.**

One Māori māmā was upset to find that hospital staff had forgotten to use a muka tie, despite having agreed to do so.

*I asked for a muka tie, and they just forgot to put one on baby and when I went to do a change, I was like, “Oh, why is there a plastic clamp here?” And they said, “Oh, sorry, we kind of just were in a rush and forgot.” That was kind of upsetting. That was the only thing I had really asked for that was cultural to me. (Māori 25+ years)*

* **Demonstrations of a lack of cultural respect.**

Demonstrations of a lack of cultural respect included the way in which the whenua (placenta) was discussed; losing the whenua; and threatening to dispose of the whenua.

*I feel like their choices of words can be made better. They asked me if I wanted to keep it [the whenua] or would you like to get rid of it. I just feel like that was quite culturally insensitive. So, that wasn’t the nicest. (Māori 25+ years)*

*I said I wanted it [the placenta/whenua] back and they kind of lost it. Then I had to go and ask for it back and then they found it. But yeah, that was a bit worrying after I just had baby, and I was hunting for it… It was stressful, because I thought my baby’s placenta had gone in the rubbish somewhere and just been destroyed. Like, to us, that is a treasure, and it means a lot. So, when they said that they couldn’t find it, I pretty much got up and went straight to the room and had a look and then went to the helpdesk and said, “You have cleared-out out the room, where is my baby’s whenua?” And they were, “Oh gosh, we will have to have a look and find out” …I was standing there upset, because I didn’t want what my pēpē had lived in for the last nine months just to be thrown in the rubbish. (Māori 25+ years)*

*They kept on trying to ring me to come and pick up my placenta, but I was visiting my baby in NICU, and then they threatened to throw it out if I didn’t hurry and pick it up. (Māori under 25 years)*

* **Not being able to have whānau present.**

Some Māori māmā and people who participated in this research found it difficult during the COVID-19 restrictions, because they were not able to have a support person present during scans and whānau present during and after the birth.

*We weren’t allowed any visitors, just because it was during the COVID time, which I understand… My friends and my best friend and my other family couldn’t visit me, and my mum had to go home to my little sisters. So, I was there by myself for one of the nights with a new baby. It was my first baby… Just getting used to everything and not having someone there to support me, I found really difficult. (Māori under 25 years)*

*I never videoed any of my other pēpē and because I could only have my husband in with me [because of COVID restrictions]. I really wanted to share with my mum. It was really important to have my mum there with us. And knowing that was our last pēpē, I cried when I couldn’t get that done. (Māori 25+ years)*

#### *Pasifika*

Only one Pasifika research participant identified having any specific cultural needs and they were satisfied that these were met.

*I had two different visits from people with the DHB whose job it was to check on cultural issues. Like, they were coming by our room to see how we were doing and if we needed help, or if we felt like we were being culturally respected. And I did… I let them know what I wanted to do with the placenta and things like that. (Pasifika 25+ years)*

#### Unmet identity needs

Despite what were described as the best efforts of some hospital staff, LGBTQ+ mothers and birthing parents who participated in this research reported that being in, what they described as, the *“heavily gendered, heteronormative”* hospital space, left them feeling *“scared”*; *“looked at and judged”*; *“not included”*; *“invalidated”*;and *“unseen”*.

*The world, while getting better more accepting overtime, is still a scary place for queer and non-binary people. (LGBTQ+)*

*I had this default thinking that my parenting would be wrong because I was wrong, or my family was wrong. So, it’s just taking that extra bit of effort and energy, emotional and mental energy to get to the same starting point as other new parents. (LGBTQ+)*

* + - 1. Specific examples of their negative experiences in the hospital space, included:
* **Identity** not being asked about or acknowledged, and assumptions being made (e.g., they are cisgender and in a heterosexual relationship).

*It was just a thing that was never spoken about or acknowledged… I identify as a queer person and I’m in a heterosexual relationship having a baby, so that reads one way to people. But it’s not like who I am. So, any communication was just standard, in a very typical way of, I’m a white woman in a heterosexual relationship. No room for other identities – so, I guess, I felt unseen. (LBGTQ+ disabled person)*

*We had someone say, “Oh, your turn next.” Just because someone has got the physical ability to carry a child doesn’t mean that’s going to happen or that she wants it to happen. (LGBTQ+)*

* **Being misgendered** and having to remind people of their pronouns and the parental names they wanted to use.

*I was constantly being told I was the first openly nonbinary person to go through the [name] hospital and so they didn’t really know what to do with me a lot of time. So, I needed to educate people… I put a sign on my door to try and remind people of what my pronouns were and that I’m not a ‘mum’, it’s not language that we use. (LGBTQ+)*

*In the hospital, when we had to deal with shift changes, we would see a midwife once and then there would be a different one, and then a different one. That was constant education and explaining who we were and why… It just felt like something we didn’t need to be dealing with… Suddenly, having a baby there and everything that came with a relatively traumatic birth. (LGBTQ+)*

* **Having to justify actions** outside of the (hospital) norm (e.g., breast milk in a bottle so that a non-gestational parent could be involved in the feeding).

*The plan that we had [to feed our child] wasn’t even an option, as far as most people would conceive of it. We constantly got asked about the bottle and we were like, well, it’s human milk in a bottle. But they couldn’t quite conceive of that in-between space. They were like constantly; it is one or the other. So, that binary thinking... (LGBTQ+)*

*I eventually just had to give up on the words that we wanted to use as my parental name and just go with my first name, because it was just too much for the people at the hospital to wrap their heads around. (LGBTQ+)*

* **Hospital staff taking umbrage** about using their pronouns and other than normative gendered parental names.

*[Name] had given birth and we had in our notes saying that I didn’t want to be referred to by any sort of gendered parent term and it was OK. But obviously, as shifts got handed over, the messages got morphed. At one stage, a midwife came in and was like, “Oh right. Well, I hear there is to be no gendered language around this baby. I just don’t know how I am going to do that” … We just felt like shrinking into the floor for a bit… The fact that you didn’t want to be called ‘mum’ or ‘dad’, just [names] was something very new and novel for them to cope with. (LGBTQ+)*

* **Being exposed to non-inclusive heteronormative and cisnormative language** (e.g., mums and dads, breast feeding) **and non-inclusive physical spaces** (e.g., maternity ward, mum’s only toilets).

*Even the fact that it’s called maternity… The assumption that everyone engaging in pregnancy care is maternal and is doing mother things… Why can’t they say what they actually mean? We are not talking about mothers, we are talking about pregnancy, or we are talking about babies, or we are taking about Caesareans or obstetrics or gynaecology. Like, whatever we are talking about it is not actually mothers. (LGBTQ+)*

*In terms of body part language, I think the big one was getting bombarded with breastfeeding all the time, despite how many times I asked for it not to be called that. Just wrapping their heads around that change in language proved to be a little too much for people… That is probably the part of my body that I dissociate from the most. So, that just made everything extra-difficult and confusing. (LGBTQ+)*

*How do we make it more inclusive for non-mum parents? That’s the caring parent that don’t identify as women or the dads or anyone else. It’s just how language and labels get used in hospitals. I remember when we were in NICU, there were toilets specifically labelled, ‘Mums only,’ so, not only did that mean I felt weird using it. I knew it was intended for me as the person who was pregnant, but that’s not how I identify. (LGBTQ+)*

* **The empty promises** of the hospital ‘rainbow friendly’ hospital posters.

*There were quite a few posters up around like, ‘Oh, we are rainbow friendly and tell us your pronouns.’ They made me feel less included, if that makes sense, because there was zero follow-through on that. It’s worse having the posters up and not doing that, than just not having the posters up and not doing it. (LGBTQ+)*

# Postnatal services

The services discussed in this section of the report include midwifery postnatal home health assessments and parenting education and support services for new parents.

## Midwifery postnatal home health assessments

Most mothers and birthing parents participating in this research had home health assessments from their midwife for at least four, if not six-weeks after having their pēpē/babies. What happened in the postnatal period for those under hospital team care was reported to be more haphazard, with some mothers and birthing parents saying that they had home health assessments for a few weeks and others saying they had none. Some mothers and birthing parents also had the support of lactation specialists.

#### Positive experiences

Generally, those with community midwives, with whom they had a ‘positive connection’, felt well supported during this period.

*The support was really good. My midwife came back the next morning and then she came three times within that one week to check on us. And then she came the next week after; the week after; and then the week after for her last visit. (Pasifika under 25 years)*

*My midwife was really great. She still even messages me now and sees how I am doing. So, I will definitely be having another baby with her. (Pasifika under 25 years)*

In addition to the general care and support they received, those mothers and birthing parents that needed it, appreciated the breast or chest feeding support they received from their midwife and/or lactation specialist.

*I was constantly on Zoom to the lactation specialist to watch the way I feed, to make sure I was doing it right. So, they were really helpful… They even sent over an electric breast pump to me during COVID [lockdown]. (Pasifika under 25 years)*

*After I had [name of baby], I found my midwife was super-supportive and also the lactation consultants through the hospital were amazing. They saved my boobs so many times. I had a lot of issues; like a new issue every week, and they would come down any time that I needed them to. It was really amazing. (Disabled person)*

The provision of links to other community supports (e.g., Plunket services) were also appreciated, especially by those who were struggling to adjust to being a new parent.

*I remember, one day, I felt like things had just gotten way too overwhelming and intense, and I made that really clear to my midwife. Then, at that point, she shared all these services with me… Different services that Plunket had… like community groups in town that could help with food. (Disabled person)*

#### Negative experiences

Mothers and birthing parents participating in this research who had no or poor connections with their midwives or who were under hospital team care, were more likely to feel that they didn’t receive the care and support they needed during this period.

*When the postnatal nurse came, she was just going through the motions. Like, she focused on her computer, not really engaging with me or anything. She didn’t ask how the birth went or how I was or anything. So, I just didn’t find that a good experience. (Māori under 25 years)*

*Returning home, I didn’t have one [home assessment] visit, but I thought I would probably have more because I have two babies. (Māori over 25 years)*

As discussed in Section 3.3, some mothers and birthing parents who had ended up under hospital team care, did not understand why their (LMC) midwife did not visit them postnatally, as there was no closure to the relationship.

The other sources of dissatisfaction reported during the postnatal period were related to breast and chest-feeding; in one instance, feeling pressured to breastfeed and in the other, not getting the support they needed to do so.

*The breastfeeding was going well at the Birthing Centre. But when I returned home, it was not going well… I didn’t really have a number for my midwives because, once you have given birth, you get a postnatal nurse, but they didn’t give me a number. (Māori under 25 years)*

## Education and support services for new parents

Research participants reported that signing-up to Plunket Whānau Āwhina and Well Child Tamariki Ora was easy.

They also valued the support services they received, including home visits to check on their pēpē/baby’s progress and knowing that there was someone or the PlunketLine to call, if need be.

*The Plunket lady was pretty onto it… She would just come and see me. She would just ask the usual questions and check his weight. (Pasifika under 25 years)*

*It was nice to know they were there if I needed her [the Plunket nurse]. And she encouraged me to ring her for anything and, if I didn’t want to ring her, I can just ring the Plunket line, which I have when I get paranoid and stuff. (Pasifika under 25 years)*

One research participant also experienced and appreciated the practical support provided by Plunket’s Giving People Support service (e.g., changing the sheets, giving her a break to have a shower).

*I got referred to Giving People Support, and they were great. They came around and just did some practical things. Like, they changed the sheets, held her, so I could have a shower, and played with her for a bit, so I could have some lunch. (Long-term disability)*

Expressions of dissatisfaction with these services were related to being uninformed that home visits would cease and/or wanting them to continue for longer than they did.

*I got handed over to the Plunket nurse; had about two visits, and then she just disappeared out of nowhere. (Māori 25+ years)*

*The last time I saw her [the Plunket nurse] was two months ago and they haven’t rung to make an appointment… When I do ring them, they say, “Oh yeah, we’ll call you to make an appointment,” but I haven’t heard from them in ages, which is dumb, because I thought they were supposed to check up on you. I just have the book and I thought it was supposed to be full of all their writing, but they’re pretty useless. (Pasifika under 25 years)*

*Once my midwife was finished, she referred us to Plunket. They said they weren’t going to visit because we were coming out of lockdown. So, I had to force her to come… I had to chase her for the next visit. She was going to call, but a phone consultation isn’t going to help me. They’re not going to know if she is growing or anything. Then, when she was about three months, they said I could go to the drop-in clinics. I have taken her to the drop-in clinics twice, but they are up in [name of place a long way from where she lives], so that’s about it. (Pasifika under 25 years)*

# Suggested service improvements

Reflecting a desire to improve their own and others’ experiences of maternity and perinatal services in the future, research participants suggested the following improvements to current services:

#### Address staffing issues

A common theme was the desire to see better staffed hospitals and **more midwives**, especially Māori, Pasifika, and LGBTQ+, and those specialising in home births.

*Making sure that the wards are fully staffed, so that it allows for nurses to check on you hourly. That’s my biggest one [in terms of improving services]. (Māori under 25 years)*

*I want to see people that look like me. I want to see people that are as diverse as Aotearoa looks and I don’t care if they are qualified or not. They can just be there in the services to tautoko [support]. (Māori disabled person)*

*We need a big push for more Māori midwives. As a whole, it would be nice to have more than just one Māori midwife to pick from in your region, because that is what the case is here in the [name of region]. (Māori 25+ years)*

#### Make services more inclusive

Another common theme was to ensure that **all** hapū/pregnant mothers and birthing parents, regardless of culture, identity, age, and any other ‘differences’, **felt welcomed and cared for** when experiencing maternity and perinatal services, especially in a hospital environment.

*If someone is looking at me like I am strange, I cannot feel included. (Disabled person)*

*I think it is about respecting everyone’s different culture and values because everyone is different. (Māori under 25 years)*

*[For the LGBTQ+ community this means], no normal that they are not a part of. (LGBTQ+)*

In meeting this objective, the expectation was that **everyone would be treated with understanding, compassion, and respect.**

*I know that we are not able to provide someone from each culture, so, someone that’s a good listener; non-judgemental, just listening is so important. (Disabled person)*

*Listen to what mums are saying. (Māori under 25 years)*

There was also the expectation that care, and support would be more holistic and less clinical, and that an important way of achieving this would be by **always asking about** (never assuming) **women’s and people’s cultural and identity needs**.

*I would like a more holistic approach to pregnancy and birth, not such a clinical one… [That would mean] integrating the things we mentioned, like identity, spirituality and the emotional side of things, and individual needs around those things… [Because] a person is going through a really intense, incredibly scary [time]. [It’s an] everything at once experience. So, don’t just treat them like they are a patient; like pregnancy is a disease. (Disabled person)*

*Assumptions – don’t make them. Just never ever make them… Assume you know nothing about the person and their whānau structure… Couples can be more than a man and a woman... Expect preferred names. (LGBTQ+)*

*Whoever you are working with, especially if it is first time hapū māmā, she is about to do something very important. So, just ask what is important to her and what she believes in. It’s getting to know her really. That could change a whole lot. (Māori 25+ years)*

To this end, Māori māmā and people, recommended **cultural training** for midwives, hospital staff and others working in maternity and perinatal services.

*Compulsory Treaty of Waitangi training. More training about working with tangata whenua and other people of colour. (Māori disabled person)*

*It would be nice to see a bit more education around cultural stuff with, not only midwives, but hospital staff as well… More education around our cultural needs… Learn a bit more from the tangata whenua, just so that they are aware of what some of the needs are for Māori māmā, so they are able to go in confident and help these māmā with their cultural and spiritual needs… Because, I couldn’t find a Māori midwife, it would be good if they had more knowledge, if they could do a wānanga around different cultural needs (Māori 25+ years)*

LGBTQ+ mothers and birthing parents also wanted services and, particularly, hospitals to be **more inclusive**. While the sentiment was that this was going to require a concerted effort to change, the use of inclusive (not heteronormative or cisnormative) language was identified as having the potential to go a long way to making them feel welcome.

*The idea that we introduce the class on gender and sexuality in our midwifery or whatever [training], I don’t think is a helpful way of looking at it. It has to be baked in throughout medical school. Gender is never assumed; pronouns are always inclusive. All the terminology needs an overhaul and that has to happen in Med school and everywhere. Just baked in, so culture breeds culture. (LGBTQ+)*

*Language is a powerful signal for the community – telling you, you are welcome… [It] needs to be good for everyone. Not just those who are cis[gender]. (LGBTQ+)*

#### Address the power imbalance

Some research participants, particularly disabled women, and people, wanted to see the power imbalance they experienced when interfacing with the medical system addressed by, for example, **improving ‘informed consent’ processes**. Their expectations in this regard included: making sure that mothers and birthing parents are fully informed before making decisions; that they understand that they have choices; and that they understand that their choices should be exercised without feeling pressured.

*There is a power dynamic, when someone is coming into the medical system in pregnancy and birth. Give the power back to the person making the journey. (Disabled person)*

*[There should be information] sharing the risks versus the benefits. Not just saying, this is what we do here in the hospital; this is what is going to happen to you. But like actually involving the person in the discussion and letting them know that they actually have choices. That it is actually their body and their baby and it’s actually their choice at the end of the day… Informed consent. That is really missing. (Disabled person)*

#### Support more birthing options within hospitals

Some mothers and birthing parents who had planned a home birth, but were unable to have one, wanted a ‘safe’ hospital-based option.

*Stop thinking of pregnancy and birth as a medical event that needs to be managed by medical professionals in hospitals. (Long-term disability).*

*Home birth may be preferred because it is not as frightening. [You are] able to feel safe and cocooned. (LGBTQ+)*

Māori māmā and people liked the idea of a Māori cultural birthing option in the hospital, including having harakeke kete for the whenua and muka ties available. They also wanted better promotion and access to Hapū Wānanga for all whānau who want to learn about traditional Māori birth practices, led in a Kaupapa Māori way.

*Some mums don’t have the time or the connections to be able to go and get muka ties, etc. So, have muka ties and all that available at the hospitals. (Māori 25+ years)*

*It would be great to actually have some kind of cultural birthing option… A lot of us who are Māori don’t really have kaupapa around that. So, even to learn that while being hapū would be amazing and, I guess, that proudness of giving birth as a wāhine; as a Māori. And, if you could do that in a hospital, that would just be amazing. (Māori 25+ years)*

*Hearing the other ladies say that they didn’t know about hapū wānanga. I think is the biggest thing. If I could make things my way, it would be to have the DHBs pushing these wānanga that local iwi are holding, so that all of our community know. (Māori 25+ years)*

#### Identify and remove the barriers to accessing services

Research participants wanted to see better access to maternity and perinatal services, including scans and antenatal classes. Suggestions for how to make these improvements included, better advertising of what services are available, reducing costs; and increasing service availability.

*Provide Information about how to access services, where to go, and policies that provide services for immigrants and people of colour… What is free; what is subsidised; where to go; who to talk to; who to trust. (Disabled person)*

*I feel like pregnancy-related stuff should all be funded. (Pasifika under 25 years)*

#### Improve information quality

Ideas to enhance the quality of the information targeting hapū/pregnant mothers and birthing parents, and to help ensure that they receive the content they need, included: focusing more on developing information on the platforms that appeal to younger mothers and birthing parents (e.g., YouTube, Apps); ensuring printed information is up to date; and ensuring that the language and look and feel of information is inclusive.

*We had a lot of paperwork and stuff like how dad can support mum in the early weeks. It would be easy to fix that language to include everybody. I think, just birthing person and support person. (LGBTQ+)*

*Maybe, an application for what to expect. You might have a birth plan, like… do you have a plan b or c? It would be nice if they [midwives] could put all their knowledge into an app because it’s the 21st century... A simple app to download because there is a lot of information out there and things keep changing in the health system. (Pasifika 25+ years)*

Appendix A: Methodology

The purpose of the qualitative research was to provide a deeper understanding of the experiences of mothers and birthing parents from population groups known to be poorly served by the maternity and perinatal system.

The specific objectives included, providing an understanding of:

* What maternity and perinatal services look like when they are working well and not working well, including when the cultural, identity and other needs (e.g., emotional, physical) of mothers and birthing parents are met, and not met.
* The barriers and enablers to accessing services.
* The improvements in maternity and perinatal services these mothers and birthing parents would like to see in the future.

The insights from the findings of this research, along with the findings from the 2022 Survey of Whānau/Families Experience of the Maternity and Perinatal System and the Survey of and Qualitative Research with Whānau/Families Who Have Lost a Pēpe/Baby, will be used to identify and inform service improvements.

**Limitations of this research**

It is important to note that the findings of this research are based on a small, but carefully selected, number of research participants (n=24). See sample description following.

Furthermore, it is important to acknowledge that the final sample does not reflect the diversity of each population group included in this study (e.g., the LGBTQ+ group included queer and non-binary people only).

Finally, as a qualitative research study, the objective of the research was to provide an **understanding** of the experiences of mothers and parents known to be poorly served by the maternity and perinatal system, rather than to quantify these. Therefore, while it is possible to identify variations in the responses of those who participated in the research, it is not possible to extrapolate these findings in quantitative terms (e.g., prevalence) to all mothers and birthing parents known to be poorly served by the maternity and perinatal system, or to specific groups (e.g., Māori or Pasifika). As such, the results must be regarded as indicative only, when considering the populations of interest.

**Researcher insights**

Mothers and parents were primarily motivated to participate in this qualitative research, as they hoped that their input would lead to future service improvements.

It is of note that many of those who participated in this research commented that they found their experience positive. The women and birthing parents in all groups were generous in their emotional support of one another.

However, research participants were particularly keen to share their negative experiences, with the hope that other mothers’ and people’s experiences in the future would be more positive.

Against this background, the research was completed as follows:

**Expert Advisory Group**

An Expert Advisory Group (EAG), for both the survey and this qualitative research was established, and included the following members representing the diverse perspective of stakeholders within the maternity sector:

* Dr Lesley Dixon of the New Zealand College of Midwives.
* Jade Chase, Chief Advisor Pae Ora - Māori Health, Te Whatu Ora.
* Tish Taihia, Clinical Midwife Manager Ngā Hau Mangere Birthing Centre, representing the Pasfika community.
* Melanie Tarrant and Pania Mitchell from Sands NZ.
* Dr George Parker, representing the LGBTQ+ community.

**Sample characteristics**

A total of n=24 research participants contributed to the study. As shown in Table 1, this included Māori, Pasifika, LGBTQ+, those under 25 years and disabled people. Except for one person from the LGBTQ+ group (who was a co-parent), all research participants were mothers or birthing parents. All research participants’ pēpē/babies had been birthed in a hospital or a birthing unit.

**Table 1: Sample summary**

|  |  |
| --- | --- |
|  | **2022** |
| Māori – under 25 years (first birth) | 4 |
| Māori – 25 + years  | 4 |
| Pasifika – under 25 years (first birth) | 4 |
| Pasifika – 25+ years | 4 |
| Disabled people | 3 |
| LGBTQ+  | 5 |

 Total 24

**Recruitment criteria and approach**

Decisions about whom to include in the sample and the recruitment criteria were made in consultation with Te Whatu Ora. All participants came from population groups known to be poorly served by maternity and perinatal services.

Māori and Pasifika mothers and birthing parents were specifically recruited to include young, first-time mothers and parents (i.e., those under the age of 25 years). These recruitment criteria were included to ensure the voices of young mothers and birthing parents, and first-time mothers and birthing parents, were clearly heard.

While no attempt was made to control for any other criteria, observation suggests that the final sample was reasonably diverse in terms of research participants’ social economic realities, and where in Aotearoa/New Zealand they lived (including those from the North and South Islands and those from large urban, provincial towns, and rural communities).

Potential participants for the LGBTQ+ group were identified by Dr George Parker (the EAG member representing the LGBTQ+ community). Other potential participants were sourced by Research New Zealand through networking or were mothers and birthing parents who had identified that they would like to participate in further research, after participating in the cognitive testing, or responding to the 2022 Survey of Whanāu/Families Experience of the Maternity and Perinatal System.

Recruitment was conducted by Research New Zealand by email. Once establishing that potential participants met the recruitment criteria, they were sent an information sheet about the research (including FAQs), and a consent form (see Appendix B), which they were asked to read, sign, and return, before participating in the qualitative research. All interviews were also confirmed by email.

**The research team**

The team responsible for the research was led by Corrine de Bonnaire, (Partner, Qualitative Research, Research New Zealand), working in close collaboration with Research New Zealand’s Kaupapa Māori research partner, Teresa Taylor (TT Consulting Tāpui). Teresa (Ngāti Tūkorehe, Ngāti Raukawa, Ngāti Kahungunu, Ngāti Kuia, NZ Pākehā) was fully involved in all stages of the research process and was responsible for ensuring that cultural issues were considered and accurately interpreted in the interviews conducted with whānau Māori.

Other members of the research team included Jane Falloon (Qualitative Research Director, Research New Zealand), who assisted with the interviewing, and Mati Fryer (Research New Zealand). Mati (Te Ātiawa, Ngāti Raukawa, Cook Island Māori) was responsible for recruitment. Mati also assisted with the facilitation of the Pasifika groups and was a sounding-board when conducting the analysis and reporting in relation to Pasifika mothers and birthing parents.

**Ethics Approval**

Ethics approval was obtained from the Health and Disability Ethics Committee (HDEC) for the surveys, but they advised that this was not necessary for the qualitative research, on the basis that it was regarded as a minimal-risk observational study (Standard Operating Procedures for Health and Disability Ethics Committees Version 3.0, clause 28, page 12).

Nevertheless, the research was undertaken in a way which met established ethical standards, as set out in the National Ethical Standards for Health and Disability Research and Quality Improvement (2019).

**Interviewing**

All interviewing for this qualitative study was completed between 31 August and 28 September 2022. While the intention was to conduct six small discussion groups (each with four participants), because of recruitment difficulties and last-minute participant cancellations, two disabled people were interviewed as a dyad, and one was interviewed individually.

All interviewing was completed online as Teams meetings. The decision to conduct the group discussions online, as opposed to face-to-face, was primarily because of the COVID-19 situation. The online forum also had the benefits of being convenient for participants with pēpē/babies and provided a degree of anonymity/privacy for those wishing to leave their cameras off.

All interviewing, except for the two discussion groups with Māori and the group with members of the LGBTQ+ community, were facilitated by the primary researcher. The discussion groups with Māori were facilitated by Research New Zealand’s Kaupapa Māori research partner, and the LGBTQ+ group was facilitated by the EAG member representing this community.

Each of the group discussions, and the dyad and individual interview, were also attended by another member of the research team, whose role it was to take notes and support the facilitator. It is of note that the Pasifika groups were co-facilitated by Mati Fryer, who is of Cook Island Māori decent.

Group discussions and interviews were each 60 minutes in duration. At the beginning of each interview, respondents were asked: to confirm that they understood that their participation was on a voluntary, confidential, and fully informed basis; and for permission to audio-record and transcribe these for analysis purposes.

Discussion guides were used as an ‘aide memoir’, to ensure information requirements were consistently explored. The discussion guide, information sheets (FAQs) and the Consent form were all developed in consultation with Te Whatu Ora. See AppendixB for samples.

All research participants were provided a koha as thanks for their participation in the research.

**Analysis and reporting**

Analysis commenced during the fieldwork phase of the research and was conducted on an iterative basis. At the completion of the fieldwork stage, transcripts were read multiple times and, through a process of coding, themes relevant within and across groups were identified.

The report was written by the primary researcher in consultation with the Kaupapa Māori researcher. The close involvement of the Kaupapa Māori researcher ensured that issues of cultural significance for Māori were considered and accurately interpreted.

Appendix B: Discussion guide, Information sheet and Consent Form

Discussion Guide

Qualitative Research Stage – Terminations

Maternity Services Research (#5254)

Research purpose and objectives

*The overriding purpose of this qualitative research stage is to provide a rich understanding of women’s/people’s experiences of maternity services. This, along with the results of the survey research, will help inform improvements to maternity services and childbirth education classes, and the development of the National Perinatal Bereavement Pathway.*

*The specific objectives of the qualitative research are to provide a greater understanding of:*

* *What maternity services look like when they are working well and not working well, including when people’s cultural, identity and other needs are met and not met.*
* *The barriers and enablers to accessing maternity services.*
* *How women/people would like to see maternity services improved in the future.*

Introductions (10 min)

|  |
| --- |
| ***Objectives****: To ensure group participants are* ***fully informed and consent to participation.***  |

"Nau mai, haere mai, welcome to our focus group. Introduce self and Jane and then explain will start with a karakia, housekeeping stuff, any questions and then your introduction before we get into our discussion.

*Kia hoki ngā whakaaro ki a rātou kua whetūrangiatia, okioki atu koutou, moe mai rā.*

*Tātou ngā waihotanga o rātou mā, ngā mihi nui.*

*May we remember those who have passed away and wish them well on their journey.*

*For those of us here today, greetings to you all.*

**Reiterate the purpose of the research**:

* Te Whatu Ora asked independent researchers, Research New Zealand, and TT Consulting Tāpui Limited to undertake this research to provide insights into how maternity services are being experienced by different groups in the community (e.g., Māori, Pasifika, gender diverse people, those with long term disabilities).
* Discussions will cover what worked well and didn’t work well; how well needs (including cultural and identity needs) are being met and not met; any barriers experienced to accessing services; and the improvements they would like to see.

**Explain how the results of the research will be used:**

* The findings, along with the results of a survey that is running alongside the hui/focus groups, will be pulled together in a report for Te Whatu Ora. The findings will help inform improvements to maternity services and will contribute to the development of the National Perinatal Bereavement Pathway. The development of a national bereavement care pathway will ensure that a consistent standard of care is offered to all bereaved parents/whānau experiencing pregnancy and infant loss in Aotearoa.

**The** **voluntary and confidential** **nature of participation**:

* Te Whatu Ora are not told who attends the hui/focus groups and reporting will not identify individuals. Responses will be grouped together and reported on a thematic basis and quotes, if used, will remove any identifiable information.
* Confirm participants don’t need to answer questions if they don’t want to, and that they may withdraw from the research at any time.

**How the hui/group will be run and other housekeeping matters:**

* Confirm the length of the hui/focus group - up to 90 minutes.
* Encourage participants to be honest and frank about their experiences.
* Reassure participants that this is not a test (i.e., there are no right or wrong answers).
* Emphasise the importance of being always respectful of each other, including if they have differences of opinion (e.g., listening, not having side conversations, agreeing to disagree if there are differences of opinion).
* Explain that the hui/focus group will be audio recorded and that this will be transcribed to assist with the analysis of the findings. The audio recording, transcript any other information about group participants will remain the property of Research NZ and will be destroyed at the completion of the research.

*Confirm that participants consent to having the discussion/kōrero recorded for analysis purposes.*

*Discuss any questions/concerns about participation.*

Invite participants to introduce selves - tell us their name, where they are from and a little about their baby that brings them here today.

Group Discussion

Explain to group participants that the discussion will be broken into two parts, each of about 35-40 min. The first part will focus on the **information and advice** they received and how this could have been improved. The second part will focus on the **care and support** they received and what would have better met their needs. As well as sharing their own experiences with the group they will be asked to complete an individual exercise (hence requiring the pen and paper).

Information and advice (35 min)

|  |
| --- |
| *Objective: To understand how well the information and advice you received from your LMC and other health professionals after you learned you were going to lose your baby met your needs; and how this could be improved****.*** |

**What makes information and advice valuable: (3 min)**

*To make sure that we get the most from our discussion, we are just going to take a couple of minutes to talk about the various factors that determine whether we notice and value information and/or advice. I’ll start the ball rolling. For example, how relevant we believe the information or advice is to us personally and whether we respect who it has come from/who’s telling us…. What else determines whether we notice and value information* (e.g., preferences for form (e.g., written, verbal, visual) or channels, comprehension, amount of detail)?

**Group discussion – Examples of when information and advice needs are met and not met (e.g., information not received or that could have been better quality): (25 min)**

*For this part of the discussion, think back to the* ***information and advice*** *that you needed at the different stages of your loss.* ***What information/advise did you need/want [work through the points in time below]. How did this compare with what you got?***

* When you discovered something was wrong and were making the decision to end their pregnancy.
* In preparation for, and during the termination procedure, labour, and birth.
* During your time in hospital after pēpē/baby was born.
* In the days and weeks after pēpē/baby died.

If not already covered,*what would you have liked to have known about [discuss each of the information areas below]. What information/advise did you receive, how well did this meet you’re your needs?*

* Making memories with their pēpē/baby.
* The decisions that needed to be made in the period shortly after pēpē/baby died (e.g., how to care for baby, taking baby home, funeral arrangements).
* Why pēpē/baby died.
* Further diagnostic testing (e.g., of the placenta) or pēpē/baby having a post-mortem.

**Group discussion – Better information and advice: (5 min)**

* Thinking about the information and advice you received, what would you change so that it better met your, and your whānau/family’s needs.

Care and support (35 min)

|  |
| --- |
| *Objective: To understand how well the* ***care and support*** *provided by your LMC, other health professionals and support organisations (e.g., Sands NZ) met your needs; and how this could be improved****.*** |

**Rating scales: (5 min)**

*Before we discuss things as a group, we’d like you each to independently rate the* ***care and support*** *you received from* ***your LMC and other health professionals****. To start off can you please write 1 a – d down the left hand of your paper. On a scale of 1-7, where 1= very poor and 7 = excellent, please rate the care and support that you received [work through the list below]:*

1(a). When you discovered something was wrong and were making the decision to end their pregnancy.

1(b). In preparation for, and during the termination procedure, labour, and birth.

1(c). During your time in hospital after pēpē/baby was born.

1(d). In the days and weeks after pēpē/baby died. (Ask participants to consider any care and support they received from support organisations (e.g., Sands NZ), as well as the care and support they received from their LMC and any other health professionals, when answering this.

*Can you now write 2 a, b, c…e down the left-hand side of your paper. Still thinking about the* ***care and support*** *that you received from your LMC and other health professionals, and using the same scale, but this time where 1 = didn’t meet any of my needs and 7 = met all my needs extremely well, we are going to rate how well each of your following needs were met and respected:*

2(a) physical needs

2(b) emotional needs

2(c) cultural needs

2(d) spiritual needs

2(e) identity needs.

**Group discussion - Examples of when care and support needs are met and not met: (25 min)**

*Some of you were very satisfied with the care and support that you received at different times, while others of you were dissatisfied.* **Working through each stage, as below, ask those with high ratings** to *share examples of what your LMC and other health professionals did that made you rate the care and support you received [insert stage] so highly.* **Still focusing on the same stage,** **ask those with low ratings** to *share what happened that made you rate the care and support you received [insert stage] low:*

* When you discovered something was wrong and were making the decision to end your pregnancy.
* In preparation for, and during the termination procedure, labour, and the birth.
* During your time in hospital after pēpē/baby was born.
* In the days and weeks after pēpē/baby died.

If not already covered, briefly discuss - *how well do you believe….?:*

* your LMC and the other health professionals were trained/equipped to support bereaved whānau/parents.
* your decisions and views were listened to.
* the care and support you received helped in the grieving process.

**Group discussion – Better meeting support and care needs: (5 min)**

* *Thinking about the care and support you received at the different times discussed previously, what changes would need to be made to ensure that this better met your, and your whanau/family’s needs.*
* *Which of these changes that would make the most difference.*

Hui/focus group conclusion (5 min)

Ask group participants for final comments.

Thank participants, followed by Karakia.

Kia tau to Rangimarie irunga i a tatou katoa.

Kia mataara, kia manawanui, kia mākoha.

May peace and calm be bestowed upon us all.

Be aware, be steadfast, be kind and compassionate.

Information Sheet for Focus group participants

Te Whatu Ora | Health New Zealand - Maternity Services Research 2022

Thank you for indicating that you may be interested in participating in a maternity services’ focus group.

This sheet aims to give you some background information to help you decide if you’d like to participate, or not. In making your decision, you may like to discuss the research with others. Also, we will be happy to answer any questions you may have about the research and your involvement (see the contact details at the end of the sheet).

Whether or not you decide to take part is your choice.

**Why are you being invited to take part?**

You have been nominated to take part in a small focus group (of four participants) with others, who like you have lost a pēpē/baby in the last 2 years. Depending on the focus group you will have been nominated to participate in, you will have other things in common with the other group participants (e.g., how you lost your baby).

**What is the purpose of the research?**

What you and other focus group participants have to say about your experiences of the service you received from you Lead Maternity Carer (LMC) and other health professionals will help to improve maternity services in the future and help inform the Perinatal National Bereavement Pathway. The development of a national bereavement care pathway will ensure that a consistent standard of care is offered to all bereaved parents/whānau experiencing pregnancy and infant loss in Aotearoa.

**Who’s funding and carrying out the research?**

The focus groups are part of a larger programme of maternity services research (including survey research) being funded by Te Whatu Ora | Health New Zealand. This research is supported by the New Zealand College of Midwives and various consumer organisations, including those providing services to Māori and Pasifika peoples and organisations supporting women/people who have lost their babies (e.g., Sands NZ).

Te Whatu Ora have commissioned Research New Zealand ([www.researchnz.com](http://www.researchnz.com)) and their Māori research partner TT Consulting Tāpui Limited to carry out the research on their behalf. Researchers from these organisations will be responsible for facilitating the focus groups, analysing, and reporting the findings

**What’s involved in participating in the hui/focus group?**

Participation is **voluntary, anonymous, and confidential**.

If you choose to participate:

* **No preparation** is required.
* You don’t have to share any information you don’t want to, and you can withdraw from the research at any time.
* It will take **90 minutes of your time**.
* **Areas for discussion** will include:
	+ Whether the care and support and the information and advice you received from your LMC (e.g., midwife) and other health professionals met all your needs, including your cultural and identity needs.
	+ whether your LMC and other health professionals were trained/equipped to support bereaved whānau/parents.
	+ Whether your decisions and views were listened to and that the care and support that you received helped you grieving process.
	+ Your ideas about how the care and support and the information and advice you and your whānau/family received could be improved.
* **You will be provided with a koha** of $70 as thanks.

**What will happen to the information you provide?**

With your consent, an audio recording, written transcript, and notes will be made for the focus group you attend. This information will be collected for all the hui/focus groups being conducted and will provide the dataset for analysis and reporting. This information, along with any personal held about you (e.g., your name and contact details) will be stored securely by Research New Zealand and TT Consulting Tāpui Limited for the duration of the research and will only be accessed by the researchers responsible for the Hui/focus groups and the transcriber.

The results of this research will be published, but any verbatim (quotes) used in the report, will be anonymised, so that no one will be able to identify you.

At the completion of the research, the audio recordings, notes, and the personal details of participants (e.g., name, contact details) will be destroyed and the transcripts made from the audio-recordings will be anonymised. The anonymised transcripts will be stored indefinitely by Research New Zealand, in a secure government approved local cloud-based storage system. Access to this will be monitored and restricted.

**Will this research meet accepted ethical standards?**

The researchers abide by the ethical and professional conduct standards outlined by the ICC/ESOMAR International Code on Market, Opinion and Social Research and Data Analytics.

While this qualitative stage (i.e., the hui/focus groups) was deemed to be out of scope for Health and Disability Ethics Committee (HDEC) review and, as such, did not require HDEC approval, it will be conducted in such a manner that meets the established ethical standards set out in the [National Ethical Standards for Health and Disability Research and Quality Improvement | National Ethics Advisory Committee](https://apc01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fneac.health.govt.nz%2Fpublications-and-resources%2Fneac-publications%2Fnational-ethical-standards-for-health-and-disability-research-and-quality-improvement&data=05%7C01%7CCorrine.deBonnaire%40researchnz.com%7C267374d6f36540750b7008da758fe94d%7Cdb1e22f5d85741caa843ebc7b4903ae7%7C0%7C0%7C637951558692874211%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=pCc4u1Wbujs6S%2FBSJ9RDurd6nsdoycU5O%2BdEDUT0ul4%3D&reserved=0)

**Where can you find out about the results of the focus groups?**

At the completion of the research, Te Whatu Ora will publish a report of the findings on its website. Research New Zealand will email you a summary of the findings if you request this.

**Who should you contact if you have any other questions or concerns?**

If you would like to opt in or out of this research, or if you have any other questions or concerns you would like to discuss, please contact **Mati Fryer**, Research New Zealand (mati.fryer@researchnz.com) or 021 268 0504.

Mati is also able to refer you to the appropriate member of Research New Zealand or Te Whatu Ora to answer your query.

If you would like to talk to someone who isn’t directly involved in research, you can contact an independent health and disability advocate:

Phone: 0800 555 050

Fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@advocacy.org.nz

Website: <https://www.advocacy.org.nz>

If you would like to talk to someone about your loss, please contact Sands NZ. They are a voluntary organisation who support parents and whānau/families who have experienced the death of a pēpē/baby. Information and regional contact details, including phone numbers are available on their website - [www.Sands.org.nz](http://www.sands.org.nz/)

 

**Research Participation Consent Form**

Maternity Services Research 2022 – Qualitative Research stage

**PLEASE RETURN YOUR COMPLETED CONSENT FORM IN ADVANCE OF YOUR HUI/FOCUS GROUP TO mati.fryer@researchnz.com**

I understand the following:

* This research is being conducted by Research New Zealand limited and TT Consulting Tāpui Limited, on behalf of Te Whatu Ora | Health New Zealand.
* My involvement in this research is completely voluntary, which means I don’t have to participate in any discussions or activities in the hui/focus group that I do not want to and that I can withdraw from the research at any time, without explanation.
* My participation in this research will remain confidential to Research New Zealand limited and TT Consulting Tāpui Limited. This means that Te Whatu Ora will not know that I have taken part in the research, I will not be personally identified in any reporting and, at the completion of the research, any information that might identify me will be destroyed or anonymised.

I agree to the researchers from Research New Zealand limited and TT Consulting Tāpui Limited taking notes and audio-recording the hui/focus group I participate in. The notes, audio-recording, and a written transcript of the audio-recording, will be used for the sole purpose of helping the researchers analyse and report on the findings of the research.

Name: …………………………………………………………………………………..….. Date: ………………………………….

**If you would like to receive a summary of the report once it is written up, please provide your email address below.**

Email: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

 **If you are happy for your koha to be paid directly into your bank account, please provide your bank account details below. If you would prefer an alternative, please let us know.**

Bank account details: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_