

REPORT ON PROCEEDINGS BEFORE

SELECT COMMITTEE ON BIRTH TRAUMA

INQUIRY INTO BIRTH TRAUMA

UNCORRECTED

At Preston Stanley Room, Parliament House, Sydney on Monday 11 March 2024

The Committee met at 9:05 am

PRESENT

The Hon. Emma Hurst (Chair)

The Hon. Susan Carter (Deputy Chair)

Dr Amanda Cohn

The Hon. Anthony D'Adam

The Hon. Greg Donnelly

The Hon. Sarah Mitchell

The Hon. Emily Suvaal

The CHAIR: Welcome to the fifth hearing of the Committee's inquiry into birth trauma. I acknowledge the Gadigal people of the Eora nation, the traditional custodians of the lands on which we are meeting today. I pay my respects to Elders past and present, and celebrate the diversity of Aboriginal peoples and their ongoing cultures and connections to the lands and waters of New South Wales. I also acknowledge and pay my respects to any Aboriginal and Torres Strait Islander people joining us today. My name is Emma Hurst, and I am Chair of the Committee.

I ask everyone in the room to turn their mobile phones to silent. Owing to the nature of this inquiry, I would like to warn those in attendance and listening to this recording that evidence presented today may contain sensitive content or themes. If you feel distressed as a result of the inquiry's sensitive content and themes, please contact one of the resources available on the Committee's website. Parliamentary privilege applies to witnesses in relation to the evidence they give today. However, it does not apply to what witnesses say outside of the hearing. I urge all witnesses to be careful about making comments to the media or to others after completing their evidence. In addition, the Legislative Council has adopted rules to provide procedural fairness for inquiry participants. I encourage Committee members and witnesses to be mindful of these procedures.

Ms MARY VAN REYK, Individual, affirmed and examined

Ms TAMARA LEETHAM, Individual, affirmed and examined

Ms ALEXANDRA CRICHTON, Individual, affirmed and examined

The CHAIR: I welcome our first witnesses. Thank you for giving your time to give evidence today. I know this feels very formal, and I am sorry that we are all so far apart in the room. Please do not be intimidated by this. We just want to have a conversation with you. We are going to start with something that seems quite formal, as we go through those formal processes, and then we will move to Committee questions. Before we begin the session, I remind witnesses to avoid referring to specific names, hospitals and medical facilities in their evidence and to speak generally about the issues raised in the terms of reference. Do either you have an opening statement that you would like to begin with?

MARY VAN REYK: I do. I just wanted to start out by acknowledging the traditional custodians of the land and pay my respects to Elders past and present, and their continuing generosity and teaching us about the culture of birth connected to this country and this place. I'm speaking to you today as a person of colour and as a member of the queer community. With these identities, I have experienced 10 pregnancies, two D and Cs, two caesareans and two laparoscopic procedures. It's the learnings I gained across the 10 years spent falling on my family which leads me to make the recommendations. My three recommendations are subsidies for people from minority groups to employ lived-experience support people for each pregnancy from commencement to incorporate those experiencing fertility challenges; grieving rooms at all hospitals, which provide maternity care for parents experiencing miscarriage, stillbirth or pregnancy loss; and the extension of the hospital group midwifery practice to include difficult pregnancies and for the development of targeted roles for midwives with lived experience. Thank you.

The CHAIR: Ms Crichton, did you have an opening statement that you would like to give?

ALEXANDRA CRICHTON: No, I don't.

The CHAIR: Thank you both again for coming today. I'll now throw to Committee members to ask questions.

The Hon. SUSAN CARTER: Thank you both for being here today. We are very grateful because your experience helps us to learn. I suppose I'm most interested in your comment, Ms van Reyk, about the necessity for grieving rooms. Can you tell us something of your experience of loss at hospital and how that was managed?

MARY VAN REYK: Yes, definitely. I experienced eight miscarriages across my particular pregnancy journey. Some of those were self-diagnosed at home, but I did have a couple of instances where they were diagnosed at hospital. My first miscarriage was officially diagnosed at hospital. When it was diagnosed, I was in the waiting—I was put in the area of the hospital where women would be seeing an obstetrician or a gynaecologist. So there were many pregnant women in that waiting room, and I sat in that waiting room pretty much understanding that I was having a miscarriage. I sat there for about two hours, surrounded by pregnant women and their support people, witnessing them go in and have their appointments and come out, waiting to see—it wasn't until my partner actually advocated for me and said, "Mary can't keep sitting in this room with these women," as I was getting more and more distressed that they took me into—it was just like an observations room where they took me and ultimately gave me the news.

After having that news, I then had to walk out through that room of pregnant women, knowing that they were having normal pregnancies and having normal meetings but that I had, in some ways, ended my journey at that point. I had to walk through that room, which was incredibly difficult. Another time I was diagnosed, I was in the emergency room. It was out of hours. I had sensed that something was happening. So I'd come in, and the nurses were talking me through the fact that it couldn't be properly diagnosed until the next day but that's what it was looking like. There was a person in the bed next to me, who was very intoxicated, having their own experience of that night, but they were talking about the fact that they thought they might be pregnant and having that conversation. I remember the nurse saying to me, "I wish that your pregnancy was the one that was continuing," which I know was a nice comment from her, but it was just such a horrible place to be to know that this other person was just starting this journey when mine was finishing.

If there had been a dedicated space where I could have been taken, where I could have been separate from maternity care, I think it would have helped me understand and process and maybe ask questions more in the moment about what was happening or do some self-advocacy around what was happening. But because I was part of a different process or a different part of the hospital, it felt as if I was part of the ongoing work that was happening there. It wasn't, "This is the time for you to take a break and process." Just the exposure, I think, of my

story to people that I didn't intend to hear it, such as the person in the bed next to me or the people in the waiting room that saw me coming out crying. There was no privacy around me having received that information and then having time to process it. So that's definitely why I would recommend that.

The Hon. SUSAN CARTER: You got medical support. Was there an opportunity for psychological support, counselling support, spiritual support—any other support?

MARY VAN REYK: Yes, very much not in that moment. It was very much a process of, "We'll give you a referral," but then it was, "And we'll enact that after you've left and you've gone home." So at the time there was no offer of support. I did get a referral to a perinatal specialist counselling service, which I do credit for being incredibly supportive and helpful. However, that particular program is no longer funded, so I know it's no longer available for the women in my region, which I think is a significant loss. There is obviously the chapel at the hospital, but that wasn't really appropriate for me; it didn't feel like a safe space for me. I really would have appreciated having a space that had tools like a comfy chair for me to sit in or maybe a couch so my partner could physically sit next to me, because in those rooms your partner is sitting over there, the doctor is over there and I'm over there, whereas what I wanted was my partner to sit next to me and have that physical contact for me to feel comfortable and maybe for the doctor not to be sitting in front of a computer. Again, that indicates to me that this is a process. It's taking the process part of that and just being able to be present in the moment of that news being shared and its impact on me that I think was taken away by not having that space.

The Hon. SARAH MITCHELL: Thanks, Ms van Reyk. I'm sorry for your loss. Thank you for coming and sharing with us. I know it's not easy to talk about these things. I noticed in your submission that you also spoke about having continuation of support for further pregnancies. Obviously, there's anxiety that comes when you've had trauma. That's something that I know about as well. Can you explain a little bit more why you think it would be useful to have that continuity of care not just within a specific pregnancy but for future pregnancies as well?

MARY VAN REYK: I think it's commonly known that a protective response to people experiencing trauma is how many times do you have to tell your story. The thing that gets taken away when we do not have continuity of care is that protection of not having to tell your story multiple times. For me, because sometimes I was not believed, or my concerns were not taken seriously initially by some medical staff that I worked with, there is also that anxiety every time you meet someone new that they are going to have the perspective that this is just something you have to experience and that you shouldn't be asking for other things, whereas if you have the continuity of care, you have already had that conversation with them. When you come into a traumatic scenario, you want someone not to be here, at the start of the conversation; you want them to start the conversation as far along in their understanding of you and your circumstances as possible.

When you don't have continuity of care, it's having to start that conversation and, in some ways, educate that person on your particular experience. When you're in a moment of trauma, it's not the moment to be educating people on your experience. It's the time to be able to rest and reflect on that support and feel held, which you can't do when you're constantly seeing someone different. With my pregnancies, I wasn't able to get continuity of care because I had surgery on my uterus. So, in some ways, I was considered a risky pregnancy because my uterus could rupture. The chances of that were incredibly low. As my obstetrician once described, I had very boringly normal pregnancies both times.

It was a blessing for me, with my two daughters that I had, that those pregnancies were incident free, but that does mean that I was like, "Why can't I get onto the midwife practice, where I could have that continuity of care, when my pregnancies were actually no different to any other pregnancy that they were assisting at the time, ultimately?" I wouldn't have minded seeing an obstetrician more regularly. I appreciated the medical focus on that aspect of my pregnancy. I welcomed it because I was anxious about it. But in shifting the focus to needing to see the obstetrician, which led to me not being able to be on the midwifery program, was actually more harmful to my experience of the pregnancy, and increased my anxiety and difficulty, than if I'd been able to be on the midwife program and just had additional obstetrician meetings on top of that.

The CHAIR: I might just stop us for a moment to swear in Ms Leetham. Do you have an opening statement that you wanted to give to the Committee?

TAMARA LEETHAM: Am I able to read it off my phone?

The CHAIR: Absolutely.

TAMARA LEETHAM: Thank you for inviting me to provide evidence today. I wish I had a better emotional capacity to prepare but, even after almost two years, I wouldn't have revisited my experience if it wasn't for this inquiry. I was a homebirth transfer with a private midwife who has been a midwife longer than I've been alive. She even worked at the hospital, for 10 years, that I was taken to. I trust her, and she took me in to get

vacuum assistance, as my baby was posterior and had a prolonged second stage. Within one hour of my arrival, I was picked up from my support people and put under general anaesthetic without my consent for a caesarean. When I first arrived, the obstetrician said that I was pushing really well, that contractions were strong and consistent and that my baby was starting to turn.

It was when she asked my midwife how the fetal heart rate was recorded at home that things turned. It was recorded after each contraction, and the obstetrician said that wasn't good enough and that there were decelerations during contractions. This is normal in second stage, my private midwife argued and also confirmed with the birth unit manager the next day. The obstetrician rejected that it was normal and insisted that a fetal blood sample would be taken to test lactate. She read the results. My midwife said it was good, but the obstetrician said, "No, that's bad." My midwife argued that it was within a safe range, and the obstetrician proceeded to test again immediately, despite the procedure to be to retest within 30 minutes.

She says that the results are out of range and leaves to see the consultant. These results were not confirmed by anyone else, and I believe they were falsified to support the emergency caesarean that she forced on us. My spouse was told by the obstetrician, "If I don't do the caesarean right now, your wife and baby will die." They tell me my spouse is getting gowned up and will be there soon, and then put me on a table, put a mask on my face and tell me, "You're having general anaesthetic for this procedure." My midwife, obviously shocked, shouts to ask if I know what that means. The obstetrician screams at me to stop pushing as she tries to move my baby back up inside me.

Now I know, from reading my notes, that my baby was vertex—the prime position for vaginal delivery. My body was pushing involuntarily but, instead, I was made unconscious and my baby, my spouse and I were traumatised. There is so much more than this that I've put in my submission. It's a more detailed account that you've been provided. My midwife says she regrets taking me in and her notes read, "I have just witnessed obstetric abuse and I could not do anything to stop it from happening."

My biggest takeaways are that families are being taken advantage of at a very vulnerable time; birthing people are being disempowered; families are not being provided informed consent; obstetricians are failing to get consent before doing things to birthing people; obstetricians are not being held accountable for their actions, even after a complaint is made; obstetricians are not confident in their skills with instruments; obstetricians are either not keeping up with peer-reviewed studies that relate to their field of work or are pretending not to in order to do what they want; and people who are in the medicalised birth system are out of touch with what is normal and natural around birth.

The CHAIR: Thank you so much for sharing that with us. We're going to go back to questions now. If a Committee member has a question for you, they'll call your name.

Dr AMANDA COHN: I have two questions. The first one picks up on the previous line of questioning about mental health support. I was really interested in the perinatal specialist counsellor program you were talking about, Mary. I'd be interested to know where that was through and who was funding that. More broadly, my question is how can we provide mental health follow-up support for people who have been through traumatic experiences like you have been in a way that is genuinely accessible and makes you able to access those services.

MARY VAN REYK: Mine was through a local provider. I'm not sure what funding it was that allowed the program to happen, but it was in Wollongong—so, close to me. I think I was able to have 13 sessions through the referral to the hospital, which was absolutely integral to me beginning to process this. It was not only mental health support for me, but it was for my partner as well. He was invited to come and attend some sessions so that we could have a common language around grieving and around support within our house, which was really key to being able to support me in processing.

I think the other key factor was that I didn't necessarily use up my 13 visits before I fell pregnant again, so I was able to have that ongoing support not just after the first miscarriage but I then continued that support after it and with the subsequent pregnancies, just because I'm a bit savvy around getting support for myself. This is something that I think should be accessible more widely; they shouldn't be relying on people to be savvy about using systems. But, through getting a mental health plan, I was then able to extend it out again, and I've actually had the same counsellor who has supported me from those initial miscarriages to—I just saw two her a couple of weeks ago. I've had two children and it's been about eight years now. She has been my continuity of care, absolutely, and having her has meant that I've been able to do things like engage with this inquiry, which has been really important for my healing journey, or work out strategies around attending things such as baby showers or those kinds of things.

Without her, I'm not sure how I would have been able to continue with my normal life in using my existing supports of my family and friends. I think I would have withdrawn from them and become more isolated if I hadn't

had this one person walk alongside me for eight years—or something like that—and provide that touchstone for validation of my experience, knowledge of my supports and support strategies, and then being able to practically apply them as I move through scenarios across the eight years. She supported me not only through my miscarriages but also, ultimately, through my pregnancies or through surgeries related to my pregnancies. It was absolutely vital for me and, I think, something that people who give birth should have access to regardless of what their starting experience is.

Dr AMANDA COHN: I have a very quick follow-up question, and I'd love to hear from our other witnesses too. The counsellor that you've accessed sounds like an incredible support. With that mental health care plan, are you still having to pay a gap fee to access it?

MARY VAN REYK: Yes, I am, and it is not insignificant.

ALEXANDRA CRICHTON: From my experience, I didn't seek what support was available because I was scared about being reported to child services, because when I was in hospital my daughter lost more than 13 per cent birth weight, I think it was. They're supposed to lose 10 per cent, I believe. But we'd had a general anaesthetic and quite a traumatic birth, so she was quite sleepy and, despite trying to feed her, I couldn't really get her to wake up. I formula fed and did everything that had been recommended, but she still lost a fair bit of weight. By that stage I had been in hospital five or six days—I can't remember how many days exactly—but they said to me, "You need to be seen again by the lactation specialist, the obstetrician and the paediatrician," even though we'd been seen by those three people multiple times throughout. She was physically healthy. There was nothing to indicate that she couldn't go home with me. She didn't have jaundice. They were checking her sugars. They were doing all of those things that you do prior to discharge, and I wanted to discharge.

I wasn't mentally well. I didn't want to be in hospital. It was really stressful to be there. We needed to go home. It was Christmas time. It was peak COVID. I drove a manual car. I didn't have anybody to pick me up. I had arranged for someone to come and get me. All of these factors were coalescing, and then you get them saying to me, "If you discharge, we will report you to the child protective services." I work in the justice system, and I work with people who abuse their children. I know what that looks like. But because I was a single woman who had done IVF and who didn't have a lot of support at all, I think they just saw red flags. The problem is that the healthcare system and the mental health care system don't in any way gel in that way. They were keeping me there to have these three people see me, which took hours, as it does in a public hospital.

Then, after, I went home and I experienced postpartum depression and anxiety. I was totally isolated; I couldn't have anyone over. I thought that the baby would get COVID if somebody came over. We weren't sleeping. She had reflux. I couldn't believe what I'd done. I didn't have any bond with her and I really needed mental health support. I never was going to say anything. Every time I was asked if I was okay, I said I was. I was never wanting to be reported. Because I was stressed, I was upset, I was depressed and—I wasn't going to hurt her, but I thought that would be what they would assume if I said, "Yes, I'm stressed. Yes, I have no support. I've been through this traumatic thing and I have no support for it." I didn't feel like I could say anything. I just kept quiet. I was too scared. So I didn't even know what was available, to be honest.

TAMARA LEETHAM: I'm so sorry. From my experience, they recommended that I access the PANDA resource, but I really wasn't ready to focus on myself, because I felt that my baby was really affected by the birth trauma and seemed dissociative—wouldn't make eye contact or try to connect with anything like that—so I was really focused on trying to heal their trauma. I didn't realise that the PANDA service is only up until 12 months postpartum, but it was still too raw for me to access that way. I also had a six-week follow-up at the hospital that I couldn't get to at that time. I tried to call them to reschedule something and it just hung on me. There was no rescheduling; I just didn't attend. So there was no follow-up there. I'm not sure I could even go back into the hospital, though. But maybe when somebody makes a complaint, there could be a service—like an outreach—just to follow up. Because in the hospital I was very adamant about making a complaint, and I was in that fight. But as soon as I got home I just crumbled and there was no way I had the strength to pursue anything.

Dr AMANDA COHN: Thank you for sharing those really personal experiences. It is really going to make a difference for other people in future. I really appreciate some of this has been difficult to talk about. My last question is about your experiences as members of LGBTIQ+ communities. How do you think that impacted your experiences in hospital? What can the New South Wales Government do to better support rainbow families or unconventional families?

ALEXANDRA CRICHTON: I think from the beginning there is this idea that if you have an IVF pregnancy you're in a different category altogether. Early stages of my pregnancy they were talking about how I'd be induced, but they weren't able to tell me why. Then eventually a doctor met with me and said there's a 1 per cent chance, or something, of something going wrong after 40 weeks or of the placenta not functioning, and that was just the hospital's policy. So the expectation was that that would be what I would do, but the problem is that they'd

say things like that constantly, but they'd follow up by saying, "But it's up to you," which was really frustrating, because it was like, "Hang on. You're the professional and you're telling me I need to do it, and if I go against it"—

The other thing was that I was constantly asked my partner's name. I don't have a partner. I'm a single woman who accessed IVF. I said it from the beginning. When we got to the end and the baby was out and the midwife walked in and said to me and the other woman in the room, "We're going to talk about birth control now." I was like—and they said, "No, we are all going to talk about birth control. It's really important we talk about birth control." The other girl was really interested, so she was eating it up, and I was sat there listening to this lecture. At some point I said, "I'm a lesbian," and she got really embarrassed and walked out, but I was like, "If you just let me talk or if you just considered that there could be a different possibility then you would have known and you wouldn't have looked so silly."

But, for me, it was mainly around the lack of support. It was mainly around this unconventional family that I was choosing to have—almost like I was problematic—because they just really wanted to see a man and a woman who had both gotten together and had this baby in the natural way and fit the mould. Because throughout, constantly, I was asked about my partner. "Oh, you accessed a sperm donor bank. Oh, okay." I just thought to myself, "It is 2020 and 2021. Surely this has happened before. Surely this happens often." I don't think that I'm unique. I really don't. So I found that strange throughout. There was this undertone of "too-hard basket", "difficult" and "confusing". Whereas, actually, I had a really straightforward pregnancy. Everything was quite normal about it. That failure to back information up about why decisions were being made and me just feeling like, "But why is this happening? Can someone explain this to me? Am I not being explained to because I'm making this problematic choice to go outside the expectation of the norm?"

TAMARA LEETHAM: I feel like the only thing that I could consider due to my relationship with a non-binary person would be that they didn't seem to seek consent from my partner when I was incapacitated. But I'm not sure if that's just how they do things and just abuse everyone, or whether they didn't consider our relationship as legitimate—but we are married. So I'm not sure. It's hard to know when so much else went awry.

MARY VAN REYK: I think what I would speak to is the difference between having staff who are educated on working with queer patients and those who have lived experience of having some connection to queer community themselves. My dad is a gay sperm donor and, for me, every time—we would have to go through the family history again and again, and every time I would say my dad is a gay sperm donor. It wasn't that people were saying "ugh" or anything like that, but it was that it was always they were like, "Oh, really?", and they would have questions. But then that is putting us in the realm of educator. That is making us have to educate people. And I understand they may have done courses et cetera to learn these kinds of things, but the difference with a lived experience person is that your queer family becomes a non-event and it takes the focus back onto the medical situation that's happening with you.

Just for a non-pregnancy-related example, I went and got a skin check the other day and the doctor had South-East Asian heritage, so the same as me. Often, if I say where I'm from, people will be like, "Oh, Sri Lankan heritage", and ask about Sri Lanka and talk about wanting to go on a trip there. That's lovely—like, I really appreciate that they're interested—but that's not what I'm there for. I'm there for a skin check. So when I said to this South-East Asian woman, "My background is Sri Lankan", she just went to the next thing on the form. That was appropriate for that moment and that space. When you educate people who do not have that lived experience, I think you take them some way along in that conversation. But when you're in a traumatic or in a difficult situation, you actually want someone that is much further along in that conversation. And that only really comes from lived experience. And I think that's why it's really key for me.

As you say, I had a normal pregnancy. I have a normal family. But when people do not have that experience themselves and take it as an educational opportunity, it puts the focus back on you being othered as opposed to what is actually the focus of this moment: it's a medical thing. There's a medical process happening here. Can we just talk about that, instead of talking about my family or the dynamics? "Oh, did you spend much time with your dad?", or, "Do you know your siblings?" "It's not really appropriate for us to have that conversation as part of this consultation," is what I would say if I was able to in the room.

That's the other thing that speaks to my point around having some kind of peer support or peer worker in the room with you. If someone from the queer community had been in the room with me—my partner is not able to go to hospitals. He has a lot of trauma around that from acquired disability. But having someone else in the room that I could have just looked to when someone was asking questions, and they would have been able to say, "You know, we're not really talking about this right now. We're talking about Mary's birthing plan", or whatever—that would have been great. But because it was me alone in a room, I felt the need to educate. I felt the need to advocate, because we always feel like we're advocating for queer families. "We're fine. We're normal. It's a normal

thing." But I don't want to do that in a hospital room. I want a doctor to talk to me about what's happening with my body and what's happening with my baby.

The Hon. EMILY SUVAAL: I have a quick question. Thank you all for your evidence so far and for sharing your stories with us. I will ask Ms Crichton, in the first instance, as it comes from your submission—but perhaps you could all provide some insights for me as well. I was interested in the submission where you spoke about the risk-averse nature of some of the medical and health professionals in terms of information and sharing their expertise. We've heard a bit in this inquiry about the importance of education but also the need to strike the right balance when providing education and information—how much is too much and what is not enough. I invite you to make a comment on that. What, if anything, could have been different or helpful, perhaps?

ALEXANDRA CRICHTON: I think, having had such a—I don't know what the word is, but medical-heavy getting-pregnant. IVF is such a process and you're constantly seeing doctors and having scans and whatever. I was just overjoyed that I became pregnant the first time—I didn't really expect it—and had a normal pregnancy. I wanted things to go how you expect them to go. You go and you do your calm birth course. You have all these ideas about how things are going to go. People only ever tell you the positive stories when you're pregnant, because they don't want to scare the crap out of you. Nobody says, "I had a 70-hour labour and then they had to pull the baby out with forceps and I had an episiotomy" et cetera. They go, "Oh, I had a natural birth", or, "I had seven natural births", or whatever it might be. So your expectation on yourself is that you'll be able to do that, especially as a 29-year-old. I never had any expectation that things would go differently.

Not that I was blind or uninformed. I knew that things could go wrong. I knew that birth was an incredibly risky thing to do, but I thought, "This is all progressing normally and this all seems okay." But when I first saw my midwife, from the very start she was saying to me, "Yes, you'll be expected to be induced." And I was like, "What? I don't understand. Why would I be induced? I don't have any indicators for induction. Isn't that because there's something else going on?" And she didn't know. I think she might have been a trainee or new, because she ended up leaving. I don't know whether she got fired, or what happened there, because nobody really told me. But I said, "I want to see a doctor, then. I want to talk about this induction policy around IVF. I want to understand why. I'm not saying no to it, but I'd need to understand what's going on. I want to be empowered in my choices." She was very dismissive. She was very, "Oh, we'll get to that and you're only"—I think I was only 20 weeks, or something like that. It was very early on. But I thought, "But I'm mentally preparing for this massive undertaking at 40 weeks that I have to do, and I want to know how it's going to look."

My understanding of induction was that I would be monitored more. I would not be able to move around as much. I would potentially not be able to be in the pool or in the shower. I could potentially end up with closer together, harder contractions, and I wanted it to be as "normal" as it possibly could be. I wanted the least amount of intervention possible, because that's what you expect. If there's nothing going wrong, that's what you expect. It was all very dismissive and very "she's being difficult and she's wanting to ask questions". I remember leaving there because she couldn't give me the answers I wanted. I called my GP in tears, and she was like, "Well, I can't really tell you anything, but let's figure it out," because I didn't know who to ask for help.

I felt like that was the tone for the whole way throughout. It was like I was almost being difficult in wanting more information, or I was told I'd get more information at a later date. In the lead-up to actually getting induced, which is what happened in the end, I had two episodes of decreased movements. So I went in for monitoring, as I'm supposed to, which I regret doing, because they try and say, "Well, everything looks normal but it could not be normal, so what shall we do? What do you want to do?" And it's like, "So you've done all these measures. You've done the ultrasound. You've put me on the monitor, the CTG. You've got the doctor's opinion. You've done all these different things, but your last measure is, 'But you've had decreased movements.' Well, what do I know?" I said, "But she's running out of room in there. Yes, I have decreased movements, sure—but tell me if I should actually get induced." But instead they say, "No, you need to make the decision."

Whilst I wanted to feel empowered, and I wanted to be the one that made that decision, there's in the back of your mind the whole time, "But if I go and make the decision and then something happens, it's going to be my fault." And that's what they want, because they don't want to be ones that get called up before an inquiry or get asked questions about it. Of course, you wouldn't want that. You want to be the one that makes all the sound decisions and errs on the side of caution, as a medical professional. But, as the patient, you want to be feeling empowered in your choices and well informed. You want to be well informed.

I ended up getting induced. I was 37 and, I think, a couple of days—I was 38 and one, I'm sorry. I ended up getting induced and at one point my midwife said, "Well, that's why I didn't want you to get induced", when we were having a conversation. I said, "That's not something that you ever said to me, though. You were very much like 'It's your choice and you make that decision' but now you're saying you didn't want me to get induced when I'm far along in the process." When I was in the throes of labour and I was in a lot of pain and everything

was essentially progressing normally, as it comes to induction, and I had the cord prolapse—which is a really rare thing to happen, apparently—I sat there thinking, "Is this because I got induced or not?" I don't know and I'll never know.

So then it's just the red button and you get rushed off and I had to be put under general and it was out of my control. They say to you, "These are all the risks of a C-section. What do you think? Do you agree?" And you're like, "Well, yes, of course." What are you going to say? "No, hang on, let's have a chat about this"? Someone is holding the baby inside me while I'm lying on my side with my legs open while I'm being rushed down a hallway because they're worried about the baby coming out and cutting off the circulation. How was I supposed to make an informed choice? It was all just so ridiculous at that point. And then someone said, "Have you got any questions?" And I said, "Is the baby okay?" And they said, "We're doing everything we can." And I said, "That's not what I want to hear." But before I got put under I will admit that they found her heart rate and said, "Her heart rate is normal, just so you know." So that was really reassuring.

This is a bit of a messy way to say that there is this to and fro between them being quite risk averse and them erring on the side of caution and me saying, "But give me an empirical study. Explain to me how many 29-year-olds you've had that have gone through IVF that need to be induced. Is this just because you've got all these studies on older women who have fertility issues who are in their forties because I don't see how I fit into this whole 'have to be induced' box that you're trying to say that I fit into. You're not explaining it to me, but you're also saying that I should be induced." That's my experience of that.

The CHAIR: Unfortunately, we have run out of time. Thank you all so much for coming today to give evidence. Your bravery in giving your stories and coming here and being vulnerable will help so many other women. Thank you so much to each of you.

(The witnesses withdrew.)

Mrs JESSICA NASH, Individual, before the Committee via videoconference, affirmed and examined

Mrs JESSICA HIPSLEY, Individual, affirmed and examined

Ms KRISTYN BEGNELL, Individual, affirmed and examined

The CHAIR: I now welcome our next witnesses. Thank you all for joining us. Before we begin this session, I remind witnesses to avoid referring to specific names, hospitals or medical facilities in their evidence and to speak generally about the issues raised in the terms of reference. We will now go to some opening statements. Ms Begnell?

KRISTYN BEGNELL: Thank you to the Chair and the Committee for the opportunity to present today. I would just like to acknowledge the traditional owners of the land on which we meet today, the Gadigal people of the Eora nation, and pay my respect to Elders past and present. I would also like to thank all the brave women who have shared their personal experiences of birth trauma throughout this inquiry. I am in awe of your strength and resilience. "Nothing about us, without us" is a phrase I have heard often in my six years as a consumer rep. Consumers are an asset to our health system and active involvement of consumers at all levels of the development, implementation and evaluation of health strategies and programs is integral to their success. We volunteer our time and share our perspectives as people with lived experience and with a deep commitment to the improvement of the health care system.

Standard 2 Partnering with Consumers puts the onus on health services to engage with consumers in their communities, but it's so often left to the persistence of determined consumers to get a basic level of engagement in place. Some hospitals and LHDs engage well, but others are years behind and still view consumers as complainers rather than the assets they are. I've had the opportunity to sit in on two standard 2 audits of different LHDs in New South Wales and my experience of the process left me doubting its effectiveness. My observations were that surface level questions were asked of consumers and management sitting in the room gave a feeling of being closely watched.

In 2021 I was dismissed from my role as a consumer rep at Western Sydney LHD for speaking to the media about the blanket no visitors rule during COVID. I received numerous messages from women in the LHD during this period. Most of them experienced unforgiveable trauma, with many forced to give birth alone. Despite trying all internal avenues at my disposal, the concerns of the community were ignored and I was punished for using my voice to represent them. When encouraged to complain about their treatment in hospital, many women decline for fear of how lodging a complaint will impact the care they receive. Others simply want to avoid any further contact with the people who harmed them.

Birth trauma is not necessarily a result of unmet expectations or because of how a birth unfolds. Most women I've spoken to who have experienced birth trauma put it down to the way they were treated. Common themes that run through most of their stories are communication, staffing issues and fragmented care. I know women who have lost their babies but are not traumatised by the experience because they received compassionate care by known care providers that they trusted. I have seen midwives lobbying for increased ratios for years. Simply not having to tell your story again and again to every new staff member that comes into your room would make a huge difference to women's birthing experiences. These problems are not new and they are not only affecting the women; they are also affecting the staff. Women want midwifery continuity of care, and midwives want to work in these models. It is NSW Health's responsibility to deliver those services.

We've heard throughout this inquiry about the importance of midwifery-led continuity and we've heard consumers speak about the barriers to accessing this, including those from CALD communities and with risk factors in their pregnancies. Arguably, the women who need it the most are not able to access continuity due to strict entry criteria, where they live or affordability, but these programs are also being run into the ground due to poor management and resourcing. A recent example of this is the MGP at Ryde Hospital. Just last month Northern Sydney LHD announced they would be permanently closing the MGP at Ryde. Consumers didn't find out about this until almost a year after the decision had been made. I know you're all familiar with the BHI survey, so you may be aware that Ryde Hospital has been consistently among the top-performing birthing hospitals in New South Wales for several years, along with Wyong which was also closed in 2020.

MGP is the minimum standard of care that we should have. Anything else is not evidence-based care. A NSW Health representative stated in this inquiry:

... we want women to have choice and access to care when and if they need it. We understand that continuity of care, especially with a midwife, is important to women and we are working to expand the number of different types of midwifery models of care available.

Why then are so many of our continuity models being shut down across the State and replaced with MAPS?

As a matter of urgency I believe the following solutions need to be implemented to reduce the rate of birth trauma in New South Wales: expand existing MGP and publicly-funded homebirth programs across New South Wales; invest in consumer representatives; provide free training developed by maternity consumer organisations to help them understand the system and how to effectively engage with it; provide more support for consumer reps, who are at risk of being re-traumatised working in a system that is not trauma informed; train hospital management and staff on the importance of working with consumers; and set targets for consumer reps on all committees and projects and criteria for consumer reps that they must have lived experience in that area of health and be able to evaluate their satisfaction throughout the process.

The CHAIR: Ms Hipsley, do you have an opening statement that you would like to give?

JESSICA HIPSLEY: I do. Hello, I'm here today to share my story regarding both of my births in the hope that some positive changes are made to protect other mums from enduring the same challenges. In my submission I focused on the negatives and I feel the need to amend two things. I would say that the midwives and generally all staff—except for one particular senior obstetrician at my second birth—were excellent. They were kind and compassionate, particularly the midwives who assisted me after I told them I was not comfortable after my first C-section experience. The second amendment is that I said I was sent for daily monitoring during my second pregnancy with a seven-month-old at home, but I realised after it should have read "16-month-old".

My story, and the trauma detailed in my submission, centres around the disregard for my decisions and the lack of support of physiological birthing during both pregnancies; the tactics used by obstetricians to induce fear, doubt and to coerce into a particular course of action; the power imbalance present in the maternity system and risk aversion; and the aftercare provided to traumatised mothers. I understand it may be easy to become desensitised when seeing birthing mothers is your day job, but we're all individuals and this is one of the biggest moments of our lives, even if it is just an ordinary work day for our providers. The way providers choose to support mothers, their choices and their autonomy, I feel, have a profound effect on how the birth is perceived afterwards and on recovery.

My experience of obstetricians omitting and cherry-picking statistics to undermine my choices, using recommended guidelines to coerce into outcomes that avoided risk altogether—like a C-section based on age gap alone—regardless of my choice or current presenting condition, or even fabricating high-risk situations like that of a cord prolapse when I was not at any higher risk than anyone else, is absolutely not appropriate. While the risks associated with me pushing for a VBAC were reiterated countless times, I was not informed of the inherent risks associated with undergoing a second caesarean until I was signing the consent form. This complete aversion to natural birthing based on risk while having no consideration of my recovery from recurring major surgery is incredibly jarring. For me to come out the end of my birth chapter completely traumatised is not something I even remotely considered. I had educated myself, I was flexible and I trusted my providers in my first pregnancy. And I was not prepared for jumping from induction gel to surgery and what that would mean for me, my son and our recovery afterwards.

I fought the entire way through my second pregnancy to ultimately end up in the same position. However, the support and aftercare of the midwives alleviated some of my worries. The treatment by my initial obstetrician and the conversation I overheard during my caesarean re-triggered me severely. However, trauma counselling was something that I organised outside the birth system, which is something else that I think needs to be addressed with resources available immediately. I believe that there are changes that need to be made around the model of care towards, primarily, midwifery-led care to how women are supported through birth and how we assist mothers after birth, particularly if the experience was traumatising for them.

The CHAIR: Mrs Nash, do you have an opening statement that you would like to give?

JESSICA NASH: Yes, please. I know that you have received many submissions and heard from a number of women throughout this hearing regarding their experience with birth trauma. I also know that for every story you have read or heard, there would be 10 more yet to be written or spoken. The fact is experiencing trauma in our current maternity system is a very real risk and we need to do better. Giving birth is one of the most life-transforming events any woman may experience and sometimes a situation will leave her feeling traumatised, physically and mentally. I believe it's our responsibility as caregivers who have chosen to work in this industry to then do our best to support her through her trauma and help her process it with dignity, compassion and value as a human being. I believe we can improve women's experiences by improving consumer engagement and actively listening to what women want from the maternity system.

We need better collaboration between maternity service providers, particularly those who operate independently of the health department. We need better training for perinatal health professionals regarding trauma and informed consent. We need to increase continuity-of-care models, such as MGP, homebirth and birthing centres, and save the obstetric model for when it's truly needed. We need to offer proactive follow-up

support for women by a body that operates external to the hospital system. We also need training on how to actively engage consumers through consultation. Unfortunately, there is no easy fix and I, like so many others, have been working tirelessly for decades to lessen the risk of birth trauma, with little to no improvement. This needs to be an ongoing discussion, and I thank you for your willingness to explore possible solutions.

The CHAIR: Wonderful, thank you. Before we go to questions, I apologise that we're all so far away and this feels like such a formal format. We're going to be asking some questions. If there are any questions that you don't feel comfortable with, please feel free to say so.

The Hon. SUSAN CARTER: Thank you all for being here and for taking the time. Thank you for helping us to, hopefully, help other women—for something very positive to come out of the experiences that you have all had. I guess that's my question—perhaps first to Mrs Hipsley but really for anybody else, drawing from your experiences and thinking about what did help you, what are some positive recommendations for change that you could suggest that we could consider making?

JESSICA HIPSLEY: For me, there was a lot of the unknown. When I found out I was pregnant, I did the best to educate myself. I understand that COVID threw many challenges for a lot of people, and for me it was accessing in-person birth classes and such. But I still found the experience that you think you're going to have is so incredibly different to the one that you end up with, or, in my case, it was. I wasn't prepared for the use of risk or perceived risk around the situations to be used to persuade me in a particular direction. I feel like we absolutely need to be aware of how we frame the risks for women in that State, because a risk on paper means nothing but if you're saying that it could harm your child that's a very different situation. You're not coming from a balanced position. I would say impartial risk information and time to consider what that means, instead of being hurried down the path of intervention, one-on-one support with—

The Hon. SUSAN CARTER: Could I just interrupt you there? When you talk about "impartial risk information with time to consider", is that something that you think you would've benefited from if it had been more actively discussed in prenatal education, when there's time?

JESSICA HIPSLEY: Prenatal and throughout the process as well. For my second pregnancy, I went through birth education with an incredible organisation local to me. They were excellent in explaining the risks and essentially what interventions were used to mitigate that risk et cetera. But when you get in there and you're told that the risk is this, there is a risk—for me it was cord prolapse, even though my obstetrician was completely comfortable showing me that the cord was out of the way—that constant reiteration of, "There's a risk. We need to mitigate this. What do you want to do with this?" is completely jarring because you think that everything's going fine and from all accounts it's going fine. So I feel that a bit more of a balanced approach when it comes to the language we use around risk and how we present it is crucial to women making informed choices.

The Hon. SUSAN CARTER: Sorry, I didn't mean to cut you off. I just wanted to explore.

JESSICA HIPSLEY: That's fine. I think that local hospitals should partner with local independent birth educators to provide as much information to women. I don't think there are any negatives from working together on a better solution. Because at the moment, for me, it felt like going to birth education and having that empowering conversation of, "These are your choices," and then going into the hospital and having, "These are the possible interventions. Please be flexible," is so jarring—and it doesn't need to be that way. I think if there was a partnership between the health services and independent birth educators, there might be a bit of a balance where we can use the skills that the birth educators have to help inform, like I've already mentioned, conscious changes to language used in birth to balance out the power and to empower women to make decisions. For me, a big one would be immediate access to a proper birth debrief, or services for, and trauma resourcing.

The Hon. SUSAN CARTER: When you say "trauma resourcing", what might that look like in practical terms?

JESSICA HIPSLEY: I think that potentially if you were to have a proper debrief after a birth with a person who knows and has access to all of those resources associated with helping you recover from that trauma, I think that would be crucial. I'm not entirely sure on what that would mean in terms of the actual resourcing, but a debrief before you're allowed to just go home and stew on it for weeks and feel like a failure, I think, is crucial.

The Hon. SUSAN CARTER: We've had some other evidence about debriefing, and lots of different evidence about the time at which that would be most effective, but you're suggesting that it should be before you leave hospital?

JESSICA HIPSLEY: Yes. I think, for me, it was very evident that I was not okay immediately afterwards. So, very quickly, I ended up in a caesarean which was not where I expected to be—because of the circumstances and stresses, I suppose. I wasn't able to bond with my son; my milk didn't come in. And before I left the hospital

I was having panic attacks whenever I tried to feed him. Considering some of the midwives came in to assist me, I think that that is fairly evident that something is not going according to plan. So I feel like if you can see a woman is struggling at that point, that would be the time to bring in the resources.

Dr AMANDA COHN: I had a question for Ms Begnell about your experiences as a consumer representative. We've had loads of recommendations through submissions for better co-design, better consultation. In your written submission you said that sometimes that can feel tokenistic. I'm interested in that specific detail of what a better process looks like or if you've had experience of a good consultation process and how we can implement that.

KRISTYN BEGNELL: An example comes to mind immediately of a not so good one, which is I was asked once by a certain hospital to join a midwifery committee even though I said to them, "I don't represent the women. I'm not representative of the demographic in your area." This area was in Western Sydney, which has a high Muslim population which I felt not qualified to represent their needs when it comes to maternity care. I suggested that I could help them find someone better suited and they said, "No, it's okay. You'll do." They just want a bum on a seat for that committee so that they can say, "We consulted with consumers." It needs to be consumers with lived experience, definitely.

I've heard of committees at some Sydney hospitals that have consumers there that have no experience of the health condition that they're discussing. This is outside of maternity care. I've also heard from hospital staff that often the consumers don't understand a single word that's being said in the meetings. And I understand it's a difficult thing to balance, because some of these meetings are very acronym heavy and they flow very quickly, but consumers need to be empowered to ask questions when they don't understand something, either before the meeting or after or during. The LHD that I'm with at the moment does things well because we have a consumer manager who first of all will ask us if we're interested in joining this committee, introduce us to everybody, there's a running agenda item for all meetings that gives consumers a dedicated spot to ask questions and clarify things, and also we can speak to her outside of the meetings about things we don't quite understand or if we feel we're not getting anything or contributing anything to that meeting. So it needs to be two-way, and I've experienced both.

The CHAIR: I might jump in with a question to Mrs Nash. You said that in your work as a doula you've seen the dead baby card played more times than you can count. Can you talk to us a little bit more about this and why you think this is happening?

JESSICA NASH: I can't really speak as to why it's happening but it sort of relates to what Mrs Hipsley said before. It's the way that statistics are presented to women and there's always that fearmongering, and I understand that we are talking real risks. In some situations it's a matter of life and death. But there's a difference in, say, a particular statistic when it comes to uterine rupture when they say the chance is doubled when you go to a certain stage of the pregnancy. The risk may be from 0.02 to 0.04, which is still a very minuscule real risk, but that's not relayed to the woman: It's that the chance is doubled. So she, being in that primal brain where she just wants to protect her baby, is just quite panicked and distressed by that. I have seen it in person a number of times said to a woman, "Do you want your baby to die?" when she wants to consider an option that's being forced on her—really, is the word for it—or if she wants to take time to think about it or if she wants to decline it. That's just not at all appropriate, in my opinion.

The CHAIR: Ms Begnell, you said in your submission that you were given one minute to consent to the emergency C-section and appendix removal and also you gave an example of midwives expressing milk without consent. I'm just wondering if you feel comfortable to talk about the impacts that that has had on you during that birthing process and afterwards, and then also just so that the Committee sort of can better understand those experiences—I know we've talked a lot about informed consent but how that should be delivered as well.

KRISTYN BEGNELL: I had planned a homebirth for my first pregnancy. This was before my midwife had visiting rights, so I did have a private obstetrician as well, who I met twice in my pregnancy. Caesarean was never explained as a potential thing, and I didn't ask either, because, admittedly, I was very much in a frame of mind that I didn't want to jinx myself. I was very naive and felt, "I'm just going to channel all my energy into the birth experience that I want," but I was in hospital for a long time. I got there at about 10 o'clock at night, so it was about 10 hours before it was explained to me that a caesarean was needed. There was time throughout the night to explain that to me, and nobody did, I think, for wanting to protect me from panic or upset, but, really, that's not what was best for me in that moment.

I went in with acute appendicitis, very pregnant, and nobody wanted to take ownership of the situation, so when the obstetrician came in in the morning, it was full steam ahead, straight into surgery, and a minute after he arrived, I signed the form. I only know this because I requested my notes from the hospital and pieced the time line together afterwards. That just sent me into a full-blown panic. Also, being told that my husband and my

mother couldn't come in with me, that I was going to be put under general anaesthetic and that there was a risk of hysterectomy—that's one of the things on the consent form. It was too much all at once, and I think that could have been explained to me throughout the night in smaller doses. This is what could happen. It doesn't have to be delivered in a scary way, but it's a lot better than leaving me there all night to think, "They're just going to send me home and I will have my homebirth in a couple of weeks." Letting me down slowly would have been better.

The Hon. EMILY SUVAAL: Thanks to you all for appearing today for our inquiry. I might start with a question to you again, Ms Begnell. In your opening statement you talked about the MGP model and that midwives want to work in that model. Could you let us know how you arrived at that, because we've heard some conflicting evidence about MGPs in terms of the ability to be able to staff them effectively, given the constraints, particularly around rostering requirements for midwives and them having caring arrangements and that sort of stuff?

KRISTYN BEGNELL: Yes. There are a couple of studies I would be happy to send through afterwards, which are surveys of midwives' preferences—midwives and student midwives. The majority of them do want to work in continuity.

The Hon. EMILY SUVAAL: Sorry, New South Wales studies?

KRISTYN BEGNELL: Yes, and there's another one which focuses on regional areas as well, and it talks about MGP as being a model which would attract midwives to regional areas, but the issue is that midwives want to work in that model but not necessarily be on call, because they associate that with burnout. There is another study about management of MGPs and how supportive management is essential to their survival and also for preserving the midwives and avoiding burnout. The research—those midwives do want to work in the models, but the models aren't being managed effectively to avoid burnout.

The Hon. EMILY SUVAAL: You mentioned, "Particularly for regional areas." I just invite you to make comment on some of the issues that we face, particularly in New South Wales, around staffing and that being, obviously, more acute in regional areas. You mentioned Ryde Hospital and its MGP earlier. My understanding with that particular MGP was that they were unable to staff that effectively and that births had been in quite significant decline. On the one hand, it's great to have these MGP models, but when you've got midwives that effectively only have one birth a month and it's insufficient to meet their clinical competency requirements—which is a requirement of their registration—how do we balance and provide the models that women are wanting to receive where they want to receive it, in a safe way, but also the issues that we are facing around staffing and around attracting and retaining midwives?

KRISTYN BEGNELL: I think it comes down to supportive management again, because with the Ryde example, I've seen a report from 2012 which recommended that they do a better job of advertising the MGP to the community. The demand is there, but women often don't know about it until it's too late; the spots are so limited. I think that's the case with MGPs and publicly funded programs everywhere. You have to know that it exists before you even fall pregnant or you don't stand a chance of getting in. It's very uncommon to see a hospital advertise this program. I think Westmead is an example where their midwives actually wear a badge that states, "Ask me about homebirth," but often you have to ask the question, and even on their websites you have to click through seven different pages to get to any information on the publicly funded model.

I think that this is a situation that they create to some extent. When a staff member leaves, they often don't advertise to replace them, and that's definitely what I've heard about Ryde from the midwives who've worked there. They describe it as slowly the oxygen is turned off to the model to the point where it's not sustainable anymore. But we've done a survey of women in that area and 84 per cent of them want birthing services at Ryde, so I just don't think it's a case of not enough demand.

The Hon. EMILY SUVAAL: Yes. To play devil's advocate, I live in the Hunter Valley and I'd love birthing services at Cessnock Hospital, which there once were, but they can't be safely provided. So we are in this dilemma whereby we have to be able to provide a safe service for women and ideally meet their needs, but, for example, it's a 40-minute drive for any of us living in the Hunter to access the nearest birthing unit.

KRISTYN BEGNELL: Yes. I think it's a different story in regional areas like that. That's where maybe using privately practising midwives to their advantage could help. I'm not an expert on regional birthing services, but maybe it's an issue of funding. I did hear somewhere in this inquiry that, in Queensland, midwives are paid more to work in an MGP model, but don't quote me on that. I'm pretty sure I heard someone say that in one of the hearings. So I'm sure there are ways that they could attract the staff, but it's really not a consumer's problem to solve.

JESSICA NASH: Could I add something there?

The Hon. EMILY SUVAAL: Yes, go Jessica.

JESSICA NASH: I live in a regional area and one of the issues we're having with staffing is in our most recent cohort of student midwives we had 30 begin the training and just three will complete the course, because the other 27 could not sustain their lifestyle while doing unpaid clinical hours.

The Hon. SARAH MITCHELL: Thank you all for coming or for appearing online. It's really important we hear from women with lived experience. I picked up a common thread through all three of your submissions around lack of respect through your experiences. Ms Begnell, you talked about going through the process when your baby was in NICU and not being the first to hold or see her, which would be very traumatic, notwithstanding what you had been through with your birth. Mrs Hipsley, you also spoke about issues with feeding and connecting with your baby. Again, that is probably to be expected, given the trauma that you went through.

From all three of you, is there something that we could be recommending as a committee in terms of better culture and better trauma-informed training for the nurses and midwives you dealt with? Do you think it was an individual personnel thing? Ms Begnell, you spoke about some of them being very disrespectful. Is there a bigger issue we could draw attention to or make recommendations about in terms of better treatment, particularly for those who have had traumatic birthing experiences, that we could look to implement system-wide? I would be happy, Mrs Nash, to hear from you on that question as well. Maybe Ms Begnell first.

KRISTYN BEGHELL: I think it's a bit of a vicious cycle, really, because now that some years have passed since my birth experience and I have been doing consumer rep work and speaking to the nurses and midwives as well, I understand their dilemma that, more often than not, they're short-staffed, and really stressed. I mean, they see a lot of stuff in their work—it's not a job I could do—and I think it's impossible for a midwife to come from one room and not carry some of that experience with her into the next. They're under pressure, and so I understand that it would be really difficult for them to take the time needed, always. But again, it doesn't take a lot of time to use your name, like, for the health worker to introduce themselves by name and use the woman's name. Whereas, in my instance, I had a changeover in my room, a whole bunch of midwives come in and talk about me as though I wasn't even there, just barging in, no respect for the fact that I was trying to feed my baby or that I might not have had much sleep. It was very jarring, and I think little things could be done to make that a better experience.

Reading my notes before you ask me any questions would be, probably, the easiest one to fix, because I had to tell my story over and over, and that's just not on. There are lots and lots of ways, and I talk about that to medical students when I—once a term, I talk to medical students at a Sydney uni about communication. I tell them my birth story and I put little flags along the way of, "This is a time where it could've been handled differently, and it would've had a massive impact on my experience. I might not have felt traumatised by it if this had happened." So, yes, there are lots of little examples.

But really, it's just about remembering that, like somebody said earlier, that woman, this is a sacred time for her and if it's her first, second, third baby, it doesn't matter. It might be the tenth baby you've seen born that day, but just having some respect for that woman's experience. I've heard also there is—what was it—a butterfly sticker on the woman's chart, or something to indicate to other staff members that she had a traumatic experience, so that they, you know—but I think it's just better to assume that every woman who you see has experienced some form of trauma in her life, and treat them accordingly.

The Hon. SARAH MITCHELL: Thank you. Did you want to add anything?

JESSICA HIPSLEY: Yes. For me, there were a lot of comments that we hear constantly, but in terms of when you're sitting there as the mother, you think, like—it really doesn't come across. For instance, I'm sure you have all heard, "All we want is a healthy baby", which I heard so many times when I was pushing for trying to do the VBAC, and just the insinuation that I, as the mother, would not like a healthy baby out of this is outrageous, and so inappropriate. But also, "I'm just doing what I think is best", or, "We're doing this because". It just completely invalidates your entire experience, where you're expressing a particular want for a particular reason, and to have that comment or that sort of situation completely undermined is terrible. I guess this goes towards the imbalance in the room, but I mean that in terms of the health professionals as well. I had some incredible midwives try to assist me, and had the obstetrician come in over the top and completely say something different.

During my second pregnancy—I mentioned before, the cord prolapse—I was able to be shown, because I asked, where the cord was sitting. It was completely out of the way. I'd had my preliminary with the midwife and she said, "Everything's going well. This is great." I got in there expecting, "We'll wait and see", and was told, "Your baby is unsafe. Your baby is sitting in your womb unsafely. I could send you for bed rest. I could send you to hospital." Who would speak to anybody like that? When I was going for daily monitoring, because, you know, that's my care provider telling me that I should be doing these sorts of things—I went for daily monitoring and I had midwives saying, "Well, she doesn't really want you to go into labour naturally." Or when I asked for the expressing kits, I got told, "Absolutely not. I won't approve that. The midwives will call me, and I will tell them

not to because I don't want your labour starting." That is so disrespectful to anybody, let alone to someone in a vulnerable position, trying to push for their rights in a system. I think that that needs to change completely.

I understand that midwives, that obstetricians, are called in and they must see some terrible things and they've got to make the hard decisions—and thank goodness that they are there. But for a lot of the cases, it feels like talking to a brain surgeon when you've got a headache. Do you know? Like, let the natural process run and then, if there is an emergency, thank goodness you've got that trained person right there to help you, but otherwise, if that's what the mother wants, that choice that she's made, let it progress as she chooses.

The Hon. SARAH MITCHELL: Mrs Nash, did you want to add anything to that, or any comment?

JESSICA NASH: Yes, I would just like to add that there is such a general disregard for a woman's autonomy when it comes to giving birth. I have just completely lost my train of thought there, sorry. As Jessica before me just said, I'm so glad that we have the obstetric model of care because, when there is a situation that needs some assistance, it's amazing that we've got these people there to help. But I would go out on a limb and say that the majority of healthcare providers have not seen an actual, true physiological birth, and the majority of births could be natural and beautiful, and no intervention required at all, but as they've not seen that they don't have the experience in that. So they're coming from that place of managing birth, which doesn't need to be the case all the time, and that brings the disregard for the woman as the expert in her own body and what's happening in her own body.

The CHAIR: Thank you all for giving your time to tell your stories today. We really do appreciate you coming forward. Thank you for your submissions, but also, I know how stressful it is to come to one of these inquiries, so thank you so much. We really do appreciate it. It will go a long way as part of all the information that we're going to put together for the report and recommendations. Thank you all so much.

JESSICA NASH: Could I add one more thing?

The CHAIR: Yes, absolutely.

JESSICA NASH: Sorry.

The CHAIR: That's okay.

JESSICA NASH: Just in regard to debriefing birth trauma, one suggestion I had was that perhaps for every woman who births, whether the birth is traumatic or not, or ends in a loss or a healthy baby, is that a team of perinatal psychologists is assigned to check in with that woman in the postpartum period. It could be periodically, it could be immediately—two weeks, four weeks, six weeks, ongoing if she needs it—but they have that trauma-informed support. And I would suggest that these people work independently of the hospital system because, I know from women that I've spoken to, there is a hesitation to report back to the same place where you've experienced the trauma because they just kind of believe it's not going to be heard, it's not going to go any further. So perhaps the psychologist could report back to an independent body or a government body. The women are then sure that that information is going to be heard by somebody who can actually action it.

The CHAIR: Wonderful. Thank you so much for that. Thank you all again. The Committee will now break for a short 15-minute morning tea break.

(The witnesses withdrew.)

(Short adjournment)

Professor DEBORAH LOXTON, Director of the Australian Longitudinal Study on Women's Health and the Centre for Women's Health Research, the University of Newcastle, sworn and examined

Associate Professor NICOLE REILLY, Associate Professor, Perinatal and Women's Mental Health, Discipline of Psychiatry and Mental Health, School of Clinical Medicine, University of New South Wales and St John of God Burwood Hospital, and Senior Research Fellow, Rural Mental Health, Graduate School of Medicine, Faculty of Science, Medicine and Health, University of Wollongong, affirmed and examined

Ms NATALIE TOWNSEND, Research Executive Manager of the Australian Longitudinal Study on Women's Health and the Centre for Women's Health Research, the University of Newcastle, affirmed and examined

The CHAIR: Welcome back to the inquiry into birth trauma. I now welcome our next witnesses. Thank you so much for coming today. Do any of you have an opening statement that you would like to begin with?

DEBORAH LOXTON: We do. Our submission was based on data collected by the Australian Longitudinal Study on Women's Health, which regularly collects survey data from over 57,000 women from across Australia, which are then linked with various administrative datasets such as Medicare, hospitals and, importantly, the perinatal data collections. The data can be disaggregated by State, which we did for part of our submission, and includes a substantial body of qualitative, lived-experience data. In addition to this resource, we have the potential to survey or interview women on particular topics, including their birth experiences. The study is funded by the Department of Health and Aged Care, and results are regularly used to inform government policies—for example, the national women's health policy.

NATALIE TOWNSEND: In our submission, we acknowledged that definitions of birth trauma vary and chose to focus on experiences that can occur during birth that could potentially be traumatic, which included things like emergency caesarean, long labour, emotional distress during labour, birth interventions and stillbirth. Although the definition of birth trauma is varied, it is clear that potentially traumatic birth experiences are common among women in New South Wales. To get a better understanding of the extent of experiences of birth trauma and how best to support women who have had these experiences, a consensus on how physical and psychological birth trauma should be defined is essential.

NICOLE REILLY: Before I begin, I would like to pay my respects to the traditional owners of the lands on which we meet today and pay my respects to Elders past and present, and also pay my respects to any Aboriginal or Torres Strait Islander people joining today, either here in the room or online. I also thank the Committee for undertaking this enormous piece of work, which I know has been a long time in the making, and the many individuals who have so courageously shared their own personal stories, not just during the process of contributing to this inquiry but in the many years leading up to it.

Deb and Nat have provided some background around the longitudinal study already, so I'll just make a couple of short comments about other components of our submission. As we noted, there are a range of challenges in reporting on issues and outcomes relating to birth trauma, including differences in how birth trauma is defined. In our submission, as Nat mentioned, we intentionally spoke to rates of potential birth trauma, recognising that not all outcomes are experienced by individuals in the same way. We also recognise that numerical information, like the information that we included in this particular submission, can't completely capture and reflect individual experiences and that a range of methodologies going forward, including methodologies relying on data linkage and data integration and mixed methods approaches that capture patient-reported outcomes and experiences, will be essential to understanding and reporting on birth trauma, as well as its antecedents and its short and longer term impacts and outcomes.

To this end, our submission points to opportunities that can be harnessed, including ways that rich data assets that exist here in this country already, including the longitudinal study, can be used to continue to build the evidence base relating to birth trauma and as a unique data source for ongoing monitoring and evaluation activities. Thank you very much for the opportunity to contribute today.

The CHAIR: Wonderful, thank you. We'll now move to questioning.

Dr AMANDA COHN: Firstly, thank you for being here. It's wonderful to have research from a dataset as large as yours to inform our work. We're really grateful for that. What I wanted to explore was this definition issue, noting that you've picked up on potentially traumatic experiences rather than experiences of trauma, which I assume is because that's the data you've got. What would need to happen moving forward for us to better capture this data? In an ideal world, we would have a dataset as large as yours that would help us understand whether people actually experience their birth to be traumatic or not. What work needs to be done?

DEBORAH LOXTON: It's a relatively easy thing to add questions to the longitudinal study. It's a public resource that's publicly funded. Really, all that needs to happen is we need to be asked to include particular questions in the data. At the moment, the cohort who are having the most children are those born 1989 to 1995, and they have a survey in the field. As well as that survey is a survey that asks about their children and the outcomes for their children, called the MatCH survey—mothers and their children's health. That has a bit more detail in it. I think what would be helpful for us would be to understand what the definition of traumatic birth is. Every time we've presented these data—and we've done it nationally as well to the Department of Health and Aged Care—we have people who say, "I had that experience and that wasn't traumatic", and somebody else in the room who will say, "I had that experience and it was traumatic."

I think identifying the things that are around how women are experiencing the birth events that we've described would be very helpful. It would be helpful for us to know what it is exactly that you want to know and what you would like included in the dataset. The women are surveyed once every few years, but we also have capacity to run sub-studies, and this is probably a better option. That would allow us to design a survey around birth trauma in collaboration with interested parties, including women with lived experience—but perhaps representatives from government as well, ideally—so that the right questions are put into that survey. Women who have had children can be asked to complete that survey, and then it adds to the existing data that we have, which includes all their pre-conception data, all the data about their birth, and all the linked data from hospitals and the perinatal data collection and so on. Nic, I might ask if you could comment on what you were talking about before with regard to those datasets.

NICOLE REILLY: Sure. There's lots of opportunity, I suppose. Just taking another example of a sub-study where we did focus on a particular issue, which was perinatal mental health—this was over 10 years ago now. We were able to develop a sub-project of particular interest. It had an incredibly high participation rate for a sub-study, and then elements of that sub-study then became part of the main surveys that women complete every three years on average. There's also opportunity within ALSWH to look at not just psychological trauma but also physical trauma and birth injuries, and a lot of information about that is captured already. There are longer term outcomes around things like incontinence, bladder symptoms—

DEBORAH LOXTON: Bowel symptoms and so on.

NICOLE REILLY: Yes. It's a really rich dataset. It's more just around ways to ask the right questions of it and, at the same time, honour the personal experiences of women and capture those voices in a mixed-methods way so we're not entirely reliant on quantitative data. I think the other thing that is of particular value is its capacity to link with the perinatal collection and other collections that allow for follow-up beyond the time frames of the perinatal collection. Over time, things like maternity model of care will become part of the PDC in a way that it's not yet but will do in the future.

Dr AMANDA COHN: I'm also interested in the representativeness of the dataset. You would know that this Committee has an interest in particular subgroups of the population: rural and regional, culturally and linguistically diverse, First Nations, LGBTQI, age et cetera. Is that captured in your dataset or do you control for that?

DEBORAH LOXTON: To some extent. Within the two younger cohorts, who are the cohorts who have had children across the course of the study, women who have higher levels of education are over-represented. We just about have enough coverage of rural and remote Australia to be able to analyse the data by rurality. That's probably a little bit more true of the 1973-78 cohort than of the newest cohort. We've been funded by the Federal Government to refresh the cohort, which we're currently doing, so that they are more representative of culturally and linguistically diverse women. We do have sufficient women to analyse the data by sexual orientation for women who are lesbian and women who are mostly heterosexual—so, who have some bisexuality—but not for women who are exclusively bisexual. There are not quite enough women in that category to be able to do those analyses. Did I miss anything?

NATALIE TOWNSEND: I don't think so.

NICOLE REILLY: The only other point I might add is that because of the over-representation of women with higher degrees of education and so on, there is also an over-representation of women, at least previously, who have chosen private maternity care. It actually provides an opportunity to include a group of women who are traditionally under-represented in some research in this space. That's also worth noting, I think.

The Hon. EMILY SUVAAL: Thanks so much to you all for appearing today and certainly for all the wonderful work that the centre does. It's really commendable. My first question picks up from what my colleague was asking around an agreed definition of birth trauma, which I note that you recommend establishing. What definition of birth trauma does the centre recommend using?

DEBORAH LOXTON: I'm not sure we have a clear recommendation in the absence of doing some more research. I know we get told that government doesn't want to hear about more research from researchers, and I understand that. However, I'm not comfortable recommending any sort of definition at this point, beyond saying that what we identified were potentially traumatic events that have some very serious outcomes for women, and that's kind of how we did it. It was to say that women who had these experiences have a higher likelihood of depression and anxiety, and have a higher likelihood of some of these outcomes that we've listed in the submission. Whether or not the women themselves identify the event as traumatic is a really vital but missing component of that definition.

The Hon. EMILY SUVAAL: Absolutely, thank you. We've also heard in the inquiry that access to continuity of care and trauma-informed care are significant factors in birth trauma. Is this something that the centre's data currently captures about any other models of care or, indeed, private- and public-system care and access to trauma-informed care?

DEBORAH LOXTON: I'll answer a little about trauma-informed care, and then I might turn to you, Nic. We currently have a project underway examining trauma-informed care in the context of violence, but what's relevant from that project is how few people have an understanding of what trauma-informed care is. There are elements of trauma-informed care that are common but they're often not implemented, or we've found people are saying that they have not had sufficient training in order to implement trauma-informed care, at least in the violence context. I wonder if that's also true in this context.

The Hon. EMILY SUVAAL: Perhaps some research would tell us.

NICOLE REILLY: There is actually a lovely discussion paper that was published last year by our colleague from Sydney uni, which does speak to the importance of not just trauma-informed care but trauma-sensitive care. I can send that through after today. It's a very useful discussion paper. Speaking again to the issue of continuity of care and the capacity for the centre to include data relating to that, my understanding is that the main surveys do ask about whether a woman gave birth in the public or the private sector. There's capacity to embed additional questions about what that care looked like.

I think the more valuable asset, going forward, is drawing on the Maternity Care Classification System and some of the information that is provided within that. There are a lot of challenges at the moment. I think there is work underway to pull out two data items to feed into the Perinatal Data Collection, which will capture a woman's model of care at the time of her booking-in visit, I believe, and her model of care at the time of birth. Once they are freely available within the perinatal collection then they will be able to be linked with all the survey data, as well as a host of other datasets that the longitudinal study has approval to link with.

The Hon. EMILY SUVAAL: You mentioned challenges that have been faced in getting that. I'd invite you to talk more about that, just in light of the fact that we have to make recommendations about—

NICOLE REILLY: Sure. The MaCCS is a national classification system. It's managed through the Institute of Health and Welfare. I feel I'm talking slightly outside my area of expertise, but my understanding is that, at the moment, reporting into the MaCCS isn't mandatory, although around 80 per cent of services do. There are issues at the moment with being able to link data that's held within the MaCCS with the perinatal collection, but there is certainly work underway to address those challenges.

The Hon. EMILY SUVAAL: That's very interesting to hear. In terms of the data that the centre captures, I wonder if you could let us know if there is any further breakdown by some of the categories that we're looking at for this inquiry, like regional and rural locations, culturally and linguistically diverse backgrounds, socio-economic status, even prior birthing outcomes—whether that would be relevant?

DEBORAH LOXTON: Yes, we have a lot of detail on prior birthing outcomes. The very surface-level example that we gave in the submission was about previous experiences of potentially traumatic events and what happened subsequently. We could do a lot more than that. There's a lot of data there that could examine the longitudinal nature of birth trauma or potentially traumatic events.

We also could have a look at other risk factors, which is something else we haven't done. The study is funded to collect data and produce one major report each year for the Federal Government. We're not funded for ad hoc analyses in that way. But we could have a much more in-depth understanding of these outcomes were we to undertake a more detailed analysis. What we can provide later on—after today, not off the top of my head—is as much of a breakdown as we can by those groups that are your priority groups. We can provide that at a later date. I think that's relatively straightforward. But those more in-depth analyses require more statistician time than I'm able to free up in an ad hoc way.

The Hon. EMILY SUVAAL: Thank you. We were talking earlier about an agreed definition for birth trauma. Earlier you touched on trauma-informed care and definitions around that, and trauma-sensitive care. Is it fair to say that an agreed definition has not been reached in that space also, or is there further work that needs to be done if we're to make recommendations around that?

DEBORAH LOXTON: I think in the trauma-informed care space, in different pockets, there are agreed upon models of trauma-informed care. But there's nothing we've found so far that has been consistent across health services. We'd probably be better off just sending you a quick summary afterwards of what we've found so far in that space.

The Hon. EMILY SUVAAL: But certainly, suffice to say, if there's no agreed definition of birth trauma then there's no agreed definition of what is trauma-informed care for someone that has experienced birth trauma.

DEBORAH LOXTON: I think that would be fair, yes.

The Hon. SARAH MITCHELL: I apologise for not being here at the start of your evidence. Looking at the different cohorts of women in the study, did you talk at all about some of the older women who you looked at? One of the things we've heard from other medical experts has been that as you get older, your risks increase. You might have more help with conception and the like, and that sets off certain stats around things like induction and C-section. Is that what you found through your research, that slightly higher prevalence? Was it linked to maternal age or were there other factors at play as well?

NATALIE TOWNSEND: That's not an analysis we have done. That's definitely something we could look at. That's something we would expect to find, but we haven't done that analysis.

The Hon. SARAH MITCHELL: So the age split that you did, what was the rationale for that in your research?

NATALIE TOWNSEND: That's just the birth cohorts that we have in our study.

The Hon. SARAH MITCHELL: As I said, I think it has come up with a few other witnesses in previous days of hearings. While there is a higher rate of trauma for certain women, there are also medical reasons that mean that people are having babies older, and whether there's complications with that, but I understand that's quite an in-depth area. I also want to ask about the point that you make in your submission about the strong association between traumatic birth experiences and poor perinatal mental health. Again, that's something that we've heard from witnesses even this morning and at other hearings. If that experience of delivery is traumatic then sometimes the bonding, the breastfeeding—postnatal depression and the like. What can you tell us about what you found in that space? again, do you have any recommendations for suggestions that we could be making through this inquiry to help improve that process for women who have had that traumatic experience?

DEBORAH LOXTON: One of the overriding things that we've found in all perinatal mental health analyses that we've done that have taken account of birth experiences, and those that haven't, is the provision of social support being vitally important to women's wellbeing. It comes up again and again, and is an empirically sound finding. There are other things, but the two things that determine perinatal health consistently in our data are the provision of social support and previous experiences of mental health issues. Where those are related to traumatic birth, of course, you're getting this constellation of things happening beforehand. You're the perinatal mental health expert here, Nic.

NICOLE REILLY: I think in the submission—and I'll have to go back and check it—the association that we found between potential birth trauma and poorer perinatal mental health outcomes were independent of a previous mental health history, even after controlling for things like a perinatal mental health history. I know that in the most recent review of the national clinical practice guidelines for perinatal mental health, they do include some recommendations and consensus-based recommendations around asking about whether a woman experienced her birth as traumatic, as well as asking about risk factors known to be associated with traumatic birth experiences. One example of a measure that they reference in the guideline to do that is the Postnatal Risk Questionnaire. It does include a question around whether a woman found her experience of giving birth to be frightening or disappointing.

We know when we've looked at that particular question in studies that have involved clinical samples—a sample of women attending a residential parenting service, for example—from memory, around 15 per cent of women endorsed that particular item. In a mother-baby unit sample, which is a more complex and severe service space, it was more like around 30 per cent, off the top of my head. There's lots of opportunity to embed inquiry about current birth experiences and previous birth experiences into very well-established processes for mental health screening and psychosocial assessment in New South Wales, in particular. It's been embedded in routine care in this State for such a long time, and I think there's a great opportunity to build that in, provided that the

training for the staff and the support for the staff doing that inquiry is available. And, of course, provided that those referral pathways for women when they're identified as being in need of additional support are also available.

The Hon. SARAH MITCHELL: Yes, because I think it's something we've heard. Some women say that they sort of knew before they left hospital that they were going to need extra support because of the birthing experience. Others say sometimes it takes weeks or months to process, and I think that's the really hard part. But I think you're right; a lot of the perinatal support looks at whether women have had previous history of mental health, but you may find yourself having that experience because of your birth and, therefore, you didn't tick a box. I wonder whether there's more that we can do to look to recommend in that space?

NICOLE REILLY: Yes, and I guess it's about moving beyond that tick-box approach and actually using the opportunity of the postnatal psychosocial assessment to begin that conversation with women and families. I say "and families" because I know we're talking about women specifically today, in the context of the study. But there are opportunities, in an ideal world where there's that relational continuity of care for women in the postnatal environment, to begin that conversation soon after the birth and then maintain that conversation as time goes on.

The Hon. SARAH MITCHELL: Because I think, too, there have been a few women talking about feeling like, "This was something that my body should have been able to do," or what the expectation versus the reality is. I think that it's a hard thing to quantify if you're making recommendations for a system, but I do think that's a common theme coming through. How do we have that better wraparound, trauma-informed care and support, not just for the patient but their family and their support people as well, whoever that may be for them? I think that's something we need to do. Thank you.

The CHAIR: I might ask a quick follow-up question from one of the questions that was just asked around poor perinatal mental health. I'm wondering if any part of your research looked at what sort of support services should be available that aren't available to everyone, or whether there are access issues for certain groups of new mothers or anything like that?

DEBORAH LOXTON: I have to say, we haven't really examined that in detail since you did your work—

NICOLE REILLY: The perinatal study?

DEBORAH LOXTON: —for the perinatal study 10 years ago.

NICOLE REILLY: Yes.

DEBORAH LOXTON: Again, I highlight that the value of that study was that we could specifically ask questions around perinatal mental health and what helped and what didn't. One thing I will highlight from that, which I think is still true, is that when women are screened about their mental health in the perinatal period, they don't always tell the truth. There's a lot of fear around disclosing having feelings that aren't in keeping with "the perfect mother". I think that departing from what they view as the norm is very difficult for women to talk about.

So we asked women in that study, "When you were asked about your mental health, were you honest?" And so many of them—I can't remember the percentage, but I feel like it was very high—said no. The reasons that they said no were around their expectations of themselves that were very high, and not meeting those expectations, and feeling shame and fear and a lot of negative emotions around disclosing the things they were feeling. It would be great to have the opportunity to ask women about birth trauma in the same way, saying, "When people talk to you about your birth, what are the sorts of things you say and what are the things you're not saying, and why?" I think that asking those sorts of qualitative questions really gets to the heart of how you might deliver trauma-informed care in this space. I may have strayed from your question.

The CHAIR: It sort of flows into my next question. If there was funding from the Government for further research specifically into birth trauma, what are the biggest gaps in knowledge or understanding? I think you've identified one. If there was some kind of funding package put together, what research should we be prioritising?

DEBORAH LOXTON: I think identification of risk factors would be important, to try to understand what puts women at risk of experiencing birth trauma. Maybe there could be some prevention before the trauma is experienced, to mitigate the impact of whatever the traumatic event might be. Understanding what helps once trauma has been experienced—so, at the other end, what are the things that were in place for women and what was the nature of the social support, perhaps, that was helpful to women in that space? What are the elements of care that women have received that did work? We've heard about the things that don't work, and that's a really great start.

You could, in fact, analyse the 4,000 submissions that you have as a 4,000-person qualitative dataset. I think that would be well worth doing. I just want to echo something that Nic said. I can't thank you enough for the work that you're doing, and I hope you're all looking after yourselves, because that's a lot. I haven't been able

to read more than a few of those at a time without needing to take a break. As someone who works primarily in the violence space, I've been used to reading things like this, but it has been a lot. But you have a very valuable dataset right there for when things go wrong. What would be nice would be to have an equivalent dataset for when things go right so that you can identify the things that might actually help.

And then, I think it's important to then evaluate any changes that are made. We said in our submission that the data we already collect in the longitudinal study is available for analysis over time to have a look and see, once there's a policy change or a practice change, if there was an impact of that and what it was. I feel like I've missed something. Oh, yes—definitions. Find the definition of traumatic birth. What are the elements that make a birth traumatic? I think that's a very valuable piece of work. What did you say, Nat?

NATALIE TOWNSEND: I said "long term".

DEBORAH LOXTON: Yes, long-term outcomes. You can speak to that.

NATALIE TOWNSEND: I think following women who have had the traumatic experiences and seeing what happens to them over time—also women who have had that experience and then, over time, done well and, over time, not done as well, and what we could do there to help.

The CHAIR: Great. I know that your study highlighted a link between induction and higher risk of birth trauma. We've heard quite a bit during this inquiry about this cascade of interventions more likely leading to birth trauma. I'm wondering if any studies that you're aware of delve deeper into the causation for that correlation? Was it painful? Was there no informed consent? Was it unexpected? Were they lacking information? Did anything come up in your studies, or have you seen any other studies that look at the causation for that link?

DEBORAH LOXTON: We haven't exactly done causal analyses, but we do have one or two papers that looked at rurality and induction and episiotomy and a few other interventions, which we'd be happy to send afterwards. I think we could answer some of that with our existing data but possibly not the whole depth of it. Nic, are you aware of something?

NICOLE REILLY: The other thing I would add is that no single data source will be sufficient to address all of the questions and information needs that are in front of us. I think there are opportunities to pool data, to integrate data, to have concurrent efforts running at the same time. For me, one of the studies I am struck by is the Birth Experience Study. They managed to collect an unbelievable amount of information from over 6,000 women. It's full of rich, qualitative data. It uses validated measures of respect, mistreatment and so on. I think there's a lot to be learned from the methods that study used. Of course there are others, as well, but I suppose the BES study is the most prominent at the moment.

The Hon. SUSAN CARTER: I just have one question. Thank you very much for your scholarship and your advocacy. In terms of how we can adjust questions in the future and the lag in terms of when we might get data from those, are you able to speak to that at all?

NICOLE REILLY: Sure. Certainly for the routine administrative datasets, there is absolutely a time lag. I think there are efforts to speed that up from being a lag of up to two years for some of the national and State collections to more like 12 or 18 months. As a researcher, part of that lag is around ensuring that the data that you're reporting is really good quality and has been treated with integrity. That can take time, especially with qualitative work, which takes even greater lengths of time to work through. Deb or Nat, did you want to add anything around time restrictions?

NATALIE TOWNSEND: With the longitudinal study, anytime we want to change questions in that survey, that's in our hands, so that happens a lot faster than the administrative datasets. If we were adding questions to existing surveys, that has to fall into our schedule of what we're already funded to do. If it was a particular survey put together for this purpose, we can turn that around pretty fast.

The Hon. SUSAN CARTER: Okay. In relation to qualitative work, there was a comment made that women don't always tell the truth because they're driven by a sense of wanting to express normal feelings. I wondered if you had a comment on whether—are women not telling the truth or is women's experience of that truth changing over time? If we're capturing it at one point, we may not be getting a full picture of that. I wondered if you had any views about that.

DEBORAH LOXTON: I think that's absolutely true. We've demonstrated this with the violence data where frequently—we ask in every survey whether women have had experiences of violence. We noticed that women were going, "Yes, I have", and, "No, I haven't ever had this experience", and, "Yes, I have." So we did a study a few years ago where we just rang women and asked them about it. It was a qualitative study. We spoke to about a hundred women, and nearly of them all said the same thing or variations of it—that it was their mood

on the day, whether it was a particularly good mood or a particularly poor mood, that drove them to tick yes or no when it came to experiences of violence.

With the longitudinal data, because we ask them more than once, we generally are able to get to a space where we understand what has happened for that woman. In the case of the violence question, we say that if they tick yes, it's yes. The noes in that context are not correct. The other thing with the longitudinal study is that over the years, you build trust. That's why when we ask them, "Were you honest when you spoke to the provider?" they will say, "No, actually, and this is why." But if you do a cross-sectional study and you're speaking with people once, you'll have a slightly higher error rate in that space because you haven't spent 27 years building trust with your cohort.

The Hon. SUSAN CARTER: I think I recorded that you said that there was a perinatal study, and the last time you did that was 10 years ago. Is that right?

DEBORAH LOXTON: I think it was about 10 years ago.

NICOLE REILLY: Yes. It was 2011, I believe.

The Hon. SUSAN CARTER: Were there any positive outcomes of that survey?

DEBORAH LOXTON: I'll let you speak to that, Nic. You drove a lot of this.

NICOLE REILLY: There were, in ways that we didn't appreciate when we set out to do it. One of the things that we knew anecdotally at that time—the focus of that particular study was really trying to build up an evidence base around the effectiveness of mental health screening and psychosocial assessment. In Australia, the implementation of programs at that time preceded effectiveness data. We were on our way before we built the evidence base because, intuitively, it's a good thing to do. One of the things that we were able to show for the first time in an empirical way was that there were great disparities in access to these programs, particularly for women who were giving birth in the private sector. We knew this anecdotally for a really long time, but it was a unique opportunity to use data to demonstrate that. We were also able to ask women—

The Hon. SUSAN CARTER: Sorry. Were there any policy changes which flowed from that?

DEBORAH LOXTON: Clinical guidelines—

NICOLE REILLY: Some of that work is cited in the clinical practice guidelines. It was also part—

The Hon. SUSAN CARTER: I suppose what I'm asking—if that work has already been done and it hasn't effectively been reflected in policy, is that something we could fruitfully revisit if we are looking at recommendations now?

DEBORAH LOXTON: Potentially.

NICOLE REILLY: There were some changes to MBS items for obstetric services, not off the back of that work solely, but it certainly contributed to a growing evidence base. Those changes required routine assessment of mental health, drug and alcohol use, and domestic violence. They form part of pregnancy and postnatal care as part of MBS items for obstetric care. That was probably the most significant policy impact in a contributory way, rather than attributing that change entirely to that outcome. The other thing that I was going to mention has slipped my mind. I'm sorry.

The Hon. SUSAN CARTER: This may be an unanswerable question, and it picks up on questions from my colleagues. It appears that the same experience—very much on face value, with not a full understanding of all the circumstances—can be seen by one woman as traumatic and by another woman as not traumatic. I'm wondering if there's anything in your work that can help us look at some of the factors so that we can be looking at trying to promote the factors that surrounded the woman who did not feel trauma? I don't know whether that's even a possible question to ask.

DEBORAH LOXTON: We asked women if they experienced emotional distress during the birth, and I think that's as close as we get to linking trauma to particular events. We can certainly do that. We can also look backwards from women who later report perinatal mental health issues and look back and see what those associations are. I didn't bring a statistician with me. I'm not exactly sure how we would do that. But I'm sure if we throw that in front of them, they'd be able to work something out. So I think we can partially do that.

The Hon. SUSAN CARTER: We're hoping to shape positive recommendations, so we're looking for evidence of what works for women and how women are best supported so that we can minimise trauma going forward.

DEBORAH LOXTON: I'll just go back to your question about policy. I think we have a summary document that Helen put together about the perinatal changes that were made as a result of the work that was done, so we'll send that to you. That might be helpful.

The Hon. SUSAN CARTER: And if you thought there were any outstanding matters, it would be useful to have a note of those as well.

DEBORAH LOXTON: We can certainly do that.

The CHAIR: Thank you so much for coming to give your time to give evidence today. We really do appreciate it, and we appreciate all the work that you've been doing. If the Committee has any further questions, we may be in contact with you about those questions.

DEBORAH LOXTON: Thank you for the opportunity.

(The witnesses withdrew.)

Ms CATHERINE WILLIS, Pelvic Floor Physiotherapist and Member Director, Australian Physiotherapy Association, affirmed and examined

Dr JENNY KING, OAM, Head of Department of Urogynaecology, Westmead Hospital, affirmed and examined

Ms SHEREE DIBIASE, Pelvic Health Physical Therapist, Lake City Physical Therapy and Board Member, Association for Pelvic Organ Prolapse Support, before the Committee via videoconference, sworn and examined

The CHAIR: I now welcome our next witnesses. Thank you for giving your time to give evidence today. Ms Willis, do you have an opening statement that you would like to give today?

CATHERINE WILLIS: Yes, I do. I'd like to thank Emma and Susan for the opportunity to speak here today. Thank you to the whole Committee for their time, as well. The Australian Physiotherapy Association would like to thank the New South Wales Select Committee for its review of our submission and the opportunity to appear before you today. We welcome this groundbreaking inquiry. This is an unprecedented opportunity to drive systemic policy, legislative and other reforms that will improve health and quality of life outcomes for birthing parents and their families. The findings of this inquiry will have important ramifications around Australia.

The Australian Physiotherapy Association knows that far too many birthing parents suffer unnecessarily because they cannot access safe, effective and affordable pre and postnatal pelvic floor physiotherapy. One in two Australian birthing parents experiences some form of birth trauma. Many of the debilitating and demoralising injuries and symptoms associated with birth trauma can be prevented, reduced or eliminated with early intervention and ongoing postpartum pelvic health physiotherapy. This includes severe perineal tears, urinary and faecal incontinence, pelvic organ prolapse and sexual pain, which impact every facet of life, including relationships, ability to participate in daily activities and in the workforce, self-esteem and mental health.

In my 25 years as a pelvic floor physiotherapist, I have seen many cases of birth trauma that can be categorised as both physical and psychological, often a result of vaginal birth, but sometimes a result of caesarean as well. Women often have the same theme of complaints—that they felt they had no informed consent and that decisions were made on their behalf—and they often say that they had no control of their body or any decisions. In one particularly distressing case, we supported a woman who felt incapable of even leaving her front door and walking more than 10 metres due to the fear of faecal incontinence. In saying that, we also have some wonderful success stories where women are able to back up that continuity of care with staff members, including a psychologist, a midwife, a continence clinical nurse consultant and psychology, really helped them with their recovery. The direct line of support is something that they're very grateful for, and it helps them to regain confidence and their physical health.

Physiotherapy is an evidence-based, proven prevention and treatment solution to the birth trauma crisis. As the inquiry has heard from the AMA, physiotherapy is backed by doctors and those with lived experience, who have also given evidence to the inquiry. Pelvic health physiotherapists are AHPRA-regulated, advanced practice professionals with a unique extended scope and expert knowledge, skills and training. Physiotherapists are integral to collaborative, multidisciplinary, team-based obstetric care. Physiotherapists improve birth and post-birth outcomes by identifying and addressing risk factors that can lead to birth trauma and complications. The physiotherapist scope of practice includes examination, assessment, diagnosis, prevention and treatment of perineal and pelvic floor trauma, helping to reduce costly and at times ineffective surgery and reliance on medication. Pelvic floor muscle training can be delivered in both antenatal and postnatal care, preparing for childbirth and promoting recovery, and also education. But, most importantly, the trusted relationship women have with their physiotherapists is critical in dealing with what are very highly sensitive matters.

The demand for pelvic health physiotherapy is rising as a result of the increasing incidents of birth trauma and the growing recognition of its effectiveness that our workforce is adapting to meet. Women's pelvic health is the fastest growing advanced practice area of the Australian Physiotherapy Association's professional development course offerings. Despite this, we know that most women receive no or very limited access to pelvic health physiotherapy pre- and postpartum in New South Wales. State to State, access to public pelvic health physiotherapy varies considerably. New South Wales is vastly underfunded in comparison to other States, such as Victoria and Queensland. There are significant differences in pelvic health physiotherapy provision within New South Wales itself, with the Royal Hospital for Women in Sydney offering far greater access to this critical health care than other public hospitals across the State, disadvantaging women in rural and regional areas.

There is no publicly funded physiotherapy in primary health, making affordability a barrier to accessing care. Funding prenatal and postnatal pelvic health physiotherapy is critical to addressing the rising incidence of birth trauma and ensuring equity access to effective, preventive and ongoing pelvic health care. I'll leave it there

and welcome further questions. I also note that the Australian Physiotherapy Association can provide further details on the clinical scope of practice to this Committee.

The CHAIR: Sheree, do you have an opening statement that you'd like to give the Committee?

SHEREE DIBIASE: Yes, thank you. With our Association for Pelvic Organ Prolapse Support, I'm one of the board members. What we have noted is that birth trauma and menopause are the leading causes of pelvic organ prolapse. So much birth trauma has now created maternal health issues and the rise of maternal death, especially in the first through to the forty-second day. The first through to the sixth day is usually when a woman has more physical changes and physicality issues that occur. From that sixth day to the forty-second day, a woman is still at high risk if she has had any birth trauma.

Part of what I was asked to do by our board was share for a moment in my opening statement some of my own history. I am a physical therapist. I've had birth trauma—a large baby. I had a levator ani tear and also a cystocele and a rectocele. I saw five different physicians in our region and every physician told me that I was fine. I literally couldn't have a bowel movement, couldn't pee well and couldn't have sex. Finally, I saw the sixth physician. He was a trauma physician and he actually said, "Hey, I think I can help you." When you have somebody who is a pelvic health therapist, who is part of the medical world, and they are not treated well inside of that medical system, it definitely affects your emotional, your social, your sexual health, your fitness, your employment and your quality of life.

These things are why we are so passionate about having pelvic health interventions and why we're trying to do as much as we can, because we know that childbirth trauma is one of the leading causes, along with menopause, for pelvic organ prolapse. Our desire is to have interventions and to have interventions that happen more quickly, and that we're actually screening people postpartum more rapidly so that instead of waiting the traditional six weeks we're intervening quicker, at two to three weeks out, as a pelvic health physiotherapist, to actually check people, just to make sure people are well—even if it's through phone calls et cetera. We want to ensure that in the window of time from the first to the forty-second day, a woman is safe after a traumatic birth.

The CHAIR: We'll now go to questions from the Committee. Dr Amanda Cohn?

Dr AMANDA COHN: All of my questions are for both of you, so feel free to jump in, although the first one is more Australia specific, so I'll put it to Catherine. I know a lot of the recommendations in the statement are to do with Medicare funding, which is Federal, but I was particularly interested in the access varying between States. You specifically mentioned a publicly-funded program in Victoria. I was hoping you could expand on that one and how it works?

CATHERINE WILLIS: Yes, of course. I'm from Queensland, but I'm also quite well aware due to site visits to hospitals in Victoria that they have really robust multidisciplinary teams where physiotherapist input is valued and sought right at the start of the patient journey, rather than maybe 12 months to two years later once they've been on a waiting list to see a consultant doctor. We have models of care called primary contact where if a patient is referred into a public hospital for something—for example, gynaecology—if that referral fits certain criteria of symptoms or conditions then someone like a pelvic health physiotherapist can start treatment and care for that patient much earlier in their patient journey. This is something that has been running for at least 15 years and has really good evidence to support not only a reduction in the need for specialist doctor appointments, but also PREMs data, where our patients or consumers are much more satisfied with their care.

Dr AMANDA COHN: My second question is around training. I understand that women's health physio is a particularly specialised field. Certainly when I was a GP, I worked with some excellent women's health physios. But I understand that you can't just come out of uni as a physiotherapist and do that kind of really specialised work. From both of your perspectives, what's the level of training that you need in terms of courses, but also practical, hands-on placement or clinical supervision? What do we need to be providing to get more people to have those skills?

CATHERINE WILLIS: The Australian Physiotherapy Association is working closely with our college of physiotherapists to implement a really robust career pathway which includes, for example, access to level one courses, where physiotherapists can get online education and face-to-face training for a range of different conditions related to obstetric care. Then what we encourage those physiotherapists to do is to put that education into practice for a year or two before they then apply to do their next level of training, which is where they would be taught how to do things, for example, like a vaginal examination, a digital rectal examination and assessing for prolapse. All of those things are certainly very important when it comes to birth trauma. But I think this also gives our clinicians that little bit more working experience and—I don't know whether "maturity" is the right word—maybe the maturity to help deal with some of the psychological symptoms that these patients are dealing with. As

Deborah and her colleagues talked about just prior to this session, having that trauma-informed care is very important.

Dr AMANDA COHN: Did you want to add anything?

SHEREE DIBIASE: In the US it's a little bit different than that. We have two organisations. Basically, our American Physical Therapy Association has coursework that you can do and it's all postgraduate. None of this is really happening in the graduate school level. They occasionally will have a few little courses here and there that you can take. But once a person graduates, literally they do all the postgraduate work. We have Herman and Wallace that does a whole other certification. In the US, the certification that I have is a pelvic rehabilitation practitioner certification. We have to have over 2,000 contact hours and so much patient care inside of that, with coursework that's required, in order to get that particular certification.

What happens, however, is that when you have a new or younger grad that comes in, we have a 12-week mentoring program that they do and then they get a mentor for two years, who follows them and does really direct care because we do not have enough pelvic PTs in the US. We up-train people very quickly, and they are actually doing rectal and vaginal exams et cetera much earlier because we just don't have that level of physical therapist available to us. We bring them in house and we train them, and so they will actually come sometimes on their internships for 12 weeks with us, as students, and then they decide to come on with us and stay with us.

We have a full mentor program that they do because, if you look at us from the standpoint of how much it costs us to actually get somebody to that level, it's a good \$8,000 to \$10,000—just to bring somebody to that level. They have to have some sort of mentoring program and somebody who is their direct mentor that's responsible to them to actually walk them through all the steps and the stages of it. Just going to coursework and just doing those things—I feel like, in the States—has not been beneficial. It is not beneficial until they're in the clinic with us and we are actually in the physical realm, training them every day and bringing them up through—whether it's bladder or whether it's bowel, sexual health issues et cetera.

We walk them through all the hard cases and maybe start them with easier cases. But they onboard quickly inside of our clinics all over the US. They have to because we just do not have enough available to us for everybody that we need it for, because we have such a large population base of prenatal and postpartum care, plus all the other women's health issues that we're taking care of. It is definitely a burden on the clinics or hospital systems et cetera, but we have to be able to do this in order for them not to have to wait so long before we're actually teaching them the hands-on skills. We're teaching them the hands-on skills much earlier, with their mentor and with direct oversight.

Dr AMANDA COHN: From both of your answers, this is obviously very extensive. I might just come back to Catherine because I'm interested in the nuts and bolts of this in New South Wales. One of your recommendations is about incentivising physios, particularly in rural and regional areas, to take up this training. I can certainly see the benefit in that. What's the capacity like for the APA, and your available supervisors et cetera, to significantly ramp up availability of that training?

CATHERINE WILLIS: Our professional development offerings related to continence and women's health have really accelerated over the last two to three years. It's by far the biggest revenue-generating part of professional development for our Physiotherapy Association. For physios who live in rural or remote areas, it can be quite costly to take time off work, take time away from their families and travel to the major centres—for example, it might be Sydney or it might be Newcastle or it might be Wollongong—in order to attend professional development courses and then also to pay for that professional development as well. It would be wonderful to have some funding or incentivisation to help improve access for these physiotherapists.

Dr AMANDA COHN: My last question is for Catherine. Thanks, Chair, for indulging me with a lot of questions. The APA submission specifically recommends block-funding the access to pelvic health physiotherapy assessment. I was hoping you could speak to why you have specifically recommended block funding over more common fee-for-service models.

CATHERINE WILLIS: I think what this relates to is, for example, providing funding to increase FTE or staffing in the public sector, rather than improving private health insurance rebates or the Medicare-funded ability to attend private physiotherapy practices. Is that correct?

Dr AMANDA COHN: Yes, it is. It's talking about physiotherapy assessment and management as part of public multidisciplinary care teams.

CATHERINE WILLIS: Just to give an example first up, for physios who work in the private sector—and I'm certainly acknowledging that my colleagues who work in the private sector are very well educated and very well trained; they're dealing with women who have experienced birth trauma every single day—I think what

is sometimes more challenging in the private sector is having access to that truly multidisciplinary team care model. Working in a hospital setting, you can have access to a gynaecologist, an obstetrician, a continence clinical nurse advisor. You can have access to a psychologist, to the midwifery team. You can have access to a pharmacist.

We see this model working very successfully in some of the bigger areas—for example, Brisbane, where I'm from, or in Melbourne. There is a beauty in having all of those team members in one place. One of the things that I think you would have seen in some of the individual submissions to your inquiry or Committee is that for women it can be incredibly expensive to have to access individual services. You go to your GP to get a referral to a gynaecologist or you go to your GP to get a referral to a psychologist. You then have to pay for the very expensive follow-up testing to find out, for example, whether your anal sphincter repair worked or not. Trying to have that care included in our public health sector makes a lot of sense.

The Hon. SUSAN CARTER: Thank you both very much for being here. I'm conscious of time differences, so we're very grateful. I think what you have to say is really important and often overlooked. As a practical thing, I'm thinking about what the State Government can do. When it comes to Medicare schedules and such, we can recommend but we can't require. I'm also concerned about workforce, and I think it's been picked up by my colleagues. Every other thing we're hearing, we've got real workforce challenges. We know that we want specialist skilled physiotherapists to work in this. If it becomes part of public multidisciplinary care, which I think would be the gold standard, what sort of workforce challenges are there? How many more physiotherapists would we need to train? Are there practical ways that we can facilitate and encourage that training?

CATHERINE WILLIS: I think that within Australia, there's certainly evidence that we don't need to encourage physiotherapists to attend this professional development. It is our biggest growing area of professional development within the Australian Physiotherapy Association, and there's quite a lot of interest in attending online lectures or face-to-face courses. We see that; we have the evidence for that. In terms of numbers, for example, depending on the size of a hospital and how many births are at that hospital each year, we know that we also get annual data on the number of deliveries that were vaginal versus caesarean. We can kind of do a rough breakdown of what the requirements of that birthing group are each year, but also acknowledging that some women might have a perfectly wonderful, normal birth but still require physiotherapy.

I think we would need to use those statistics in order to map out what our workforce needs to look at. But certainly in some of our metropolitan areas in New South Wales—not just Sydney, but we've got to think about Western Sydney and the growing population out around Penrith; we've got to think about Newcastle; we've got to think about Wollongong; we've got to think about other regional areas—we need to have a group of physiotherapists trained in this area who have experience so that they can then be used, for example, as mentors, as Sheree has discussed, to help with more junior physios as well. We see that model of care working really well, for example, in the medical system, so we need to have something similar with physiotherapy. Susan, I've forgotten the first part of your question, sorry.

The Hon. SUSAN CARTER: It was preamble, really. As a follow-up question, to what extent would women benefit from prenatal physiotherapy? Would that be preventative? Conscious of major issues in the regions and thinking about exercise classes during COVID, is it possible to deliver prenatal physiotherapy via telehealth successfully?

CATHERINE WILLIS: Yes. That reminds me that was another point that I wanted to make with you. We do need to be innovative and use our technology much more wisely. For example, for hospitals that might have a longer waitlist for access for pelvic floor physiotherapy, we can implement telehealth group education classes. So even if we can't get each of those patients in for an individual, face-to-face appointment, we can start the education that's very important for their particular condition or symptoms much earlier on. For people living in rural and remote areas, a number of my colleagues in Brisbane will do Teams meetings or Zoom meetings with the clinicians in rural and remote areas but sometimes co-treat a patient via telehealth as well. I think we do need to be aware of utilising technology much more effectively to help with this group of patients.

The Hon. SUSAN CARTER: Is prenatal physiotherapy preventative or not?

CATHERINE WILLIS: Yes.

The Hon. SUSAN CARTER: Sorry, Lorrie, you had a comment.

SHEREE DIBIASE: I think understanding and knowing that, by the second trimester, you really need to have a musculoskeletal intervention for a prenatal mother. It is so beneficial, and there's so much data that shows, even just in the mental health space of a mother postpartum, that if she has pelvic pain and low back pain during her pregnancy, she has more likelihood of having postpartum anxiety or depression. A physio who is able to enter earlier in the cycle of all that—they prep. With pre-natal care, the time frames of labour and also the time frames

of pushing go down. The pushing stage decreases. If we can get our pushing stages down to under 10 minutes, then we're going to have less likelihood of birth trauma.

What happens with us as physios is that we're teaching the floor to be able to open better by teaching them training mechanisms prehab. We have to get them in at least the second stage, right about the stage before baby's head turns down. Usually in the thirtieth to thirty-second week baby's head is going to turn down and get into the canal. So we need that little bit earlier intervention to prep low back, prep the floor, prep the hips and make sure that you have the opening of the baby able to come down but also be able to open the outlet up. We train them all in that so that they know that this is what they're going to do during labour delivery. We're decreasing our labour times and we're decreasing our pushing times.

Pushing times are where a lot of trauma happens, because people are not aware of where the pelvic floor is and how to relax the different parts of the floor. I think the posterior anal triangle, which would be backed by anal sphincter et cetera, is way overlooked, because as baby comes down and twists, that posterior part of the floor has to be able to be open well enough. Prenatal care is a huge component of it. Many times our mums are doing 10 times better postpartum because they already know the work, because we've already trained them. Then they are in a really close relationship with us. And then, like she was bringing up, I love the idea that remote access and telehealth is going to be our next component, because we don't have access rurally. Then, suddenly, a mum who has a baby or multiple babies can't travel. But think of it: If we've been able to be with them enough sometimes before, now they do 10 times better afterwards.

CATHERINE WILLIS: Susan, if I can add as well, we do have very good evidence that things like teaching perineal massage during pregnancy can reduce the risk of perineal tears, and also looking at pelvic floor relaxation during the third trimester of pregnancy. One of my colleagues back in Brisbane is currently undertaking research to look at women with a history of genito-pelvic pain/penetration disorder and whether they do have a higher likelihood of birth trauma, and to have an awareness of what our risk factors really are. Then we can work together with our midwifery and obstetric colleagues to look at other things like the positions that are used by women in the second stage of labour when they are pushing, to help improve birth outcomes. Other things you may have heard of from midwives, for example, include supporting the perineum as the baby's head is delivered. So there is some good evidence for those things.

The CHAIR: Did you have an opening statement that you'd like to give, Dr King?

JENNY KING: Not particularly. I do have an interest in this area. I've done a lot of obstetrics, previously. I now predominantly work with pelvic floor repair, and I have a couple of research areas. One of them is anal sphincter injury, and the other one is adverse outcomes for babies and mothers delivered by elective caesarean section. So there are a lot of angles that I come at. I must admit, I hadn't really wanted to put in my submission to this inquiry, because I find the whole term of obstetric violence really unpleasant. It's like something was intended, and I just don't believe anyone gets up in the morning saying, "Which labouring lady can I give a hard time to today?"

I think our problems are with expectations. What happened to our mothers? They just popped out and had a baby and came home, didn't they? But they were very familiar with all the ladies in the street who'd had babies and the sisters, mothers and cousins. We've lost that a little bit. So I think a lot of this stuff is to do with expectations—that lack of awareness that it may not be the best day you ever had but it does have the best outcome. I think this is where the prenatal physio is so important to have an idea that, "Okay, I might be a bit bruised and battered, but I can work through this." That, I think, is what is empowering. So I would seriously support the access to pre- and postnatal physio.

Dr AMANDA COHN: Thanks for coming, Dr King. I had a question for you arising out of the APA submission, which was to do with 3D or 4D perineal ultrasound and endoanal ultrasound. My understanding is that sonography is skill and operator dependent. How much training do people need to be able to provide that sort of service? Is just having equipment enough, particularly with a view to availability of that kind of diagnostic tool in rural and regional areas?

JENNY KING: I think if you are talking about diagnosing anal sphincter injuries, fourth degree ultrasound is a bit of a con. It's the 3D that's important. But you have to keep selling equipment, don't you? But for 3D, you do need to know what you're doing. If you've got a background in ultrasound, you're probably still looking at a learning curve of six to 12 months. Having said that, by six months you'd be pretty competent. So definitely it should be possible to get that expertise out into the community. At Westmead, we use the same as the colorectal surgeons. We do the endoanal ultrasound, which goes into your bottom. It's not very big. It's about thumb size. That's probably more accurate but it's less available. It's hugely expensive. It should be possible to provide good-quality ultrasounds in rural and regional areas.

Dr AMANDA COHN: Just to clarify, when you say the endoanal ultrasound is expensive, you mean the technology is expensive?

JENNY KING: Yes. You break a probe and you think, "There's \$40,000 I'll never see again." I'm sure it doesn't have to be that dear, but you need it. So that's not an option. We have it obviously because we do ever such a lot with it.

SHEREE DIBIASE: Dr King?

JENNY KING: Yes, darling?

SHEREE DIBIASE: I'm curious. Are you using it postpartum, then? Are you talking about prenatally? When are you using it?

JENNY KING: No, postpartum. It is predominantly for diagnosis and checking repair of anal sphincter injuries.

SHEREE DIBIASE: Now there is a machine that we have in the States that's about \$5,000 that literally you can put in the perineal body and look peri-pubically and really have a good viewpoint of what the floor is doing and the anal sphincter. It's a pretty impressive thing, and it's literally probably the size of this that could go into your pocket.

JENNY KING: I'm sure. They're very good with their technology. Things do have to be validated. Even now, if you wanted a really good assessment of an anal sphincter repair, you would use an endoanal ultrasound or an MRI, again, which is expensive. Perineal ultrasound is good for screening repairs, but it has to be validated as well. People always come up with new ideas, don't they? And you wait and see. But I'm sure it will become far more readily available and cheaper.

The CHAIR: I might jump in at this point. I've got a couple of questions for Ms Willis. You highlighted in your submission that it's possible to prevent or reduce the risk of physical birth trauma in many cases, with the right interventions. For the benefit of the committee, can you talk about what those interventions are to prevent some of that physical birth trauma? I know you've covered a couple of things but just more specifically so we've got that evidence in one place?

CATHERINE WILLIS: Of course. I think that the number one thing is education and preparation so that women are aware of the birthing process. As Jenny said, birthing has been taken, for example, out of the home and into hospitals, and there's not that experience of sisters, aunts and mothers being around someone in labour to see what that process is like. Education sets up an understanding of what the birthing process is and what's normal in the birthing process. It's also very important to have these honest conversations with women and their support team about what the risk factors might be in terms of birth trauma as well.

That could be as simple as saying, "You're 42 years old. You're having your first baby. You're only 150 centimetres tall and from the last ultrasound, it looked like the baby is in the ninetieth percentile. So we might want to have a little bit of a counselling session, in conjunction with your midwife and obstetrician, about what the best type of delivery is for you in this situation." Because we all want someone to have a beautiful birth in a birth centre or birth suite, but sometimes we need to give women the facts about what is potentially going to happen, depending on their risk factors.

In terms of physiotherapy interventions, if we were to have a woman come in for a one-on-one appointment, we would usually recommend some kind of examination and, again, this might be via transperineal ultrasound or it might be via a vaginal examination where we can assess things like resting muscle tension and muscle strength, but also the ability of those muscles to relax when someone consciously lets go. We would be asking questions about things like, for example, "Do you experience any pain during sex, using tampons or during examinations?" Because that might give us an indication of some other underlying pelvic floor pathology going on.

We can teach women during physiotherapy appointments how to get a better awareness of their pelvic floor muscles activating and relaxing. We can teach women and their partners specifically how to do perineal massage, because by the end of pregnancy reaching your own perineum, believe it or not, can be quite difficult. We can also look at other things that Lorrie has mentioned as well. If someone is experiencing significant low back pain or pubic symphysis during their pregnancy, they might not be as mobile, and that could have an impact on how easy it is for them to physically labour as well.

JENNY KING: Can I add something about the education there? At Westmead, we have a very multicultural population. We have a huge number of women from South Asia, and I would have to say that they have the most complications. They're 25 per cent of our antenatal population, and they're over 50 per cent of our

complications. It's to do with the class you come from and what is talked about in that area. Seriously, we get people whose first vaginal examination is in the labour ward, and they are petrified and hysterical. They leap up the bed, and you just know that it's going to be horrible and it's going to go badly. They don't come to antenatal classes. I think we don't do them culturally very well. I think maybe they're too confronting.

It's not much good showing a picture of someone and their third baby, and she has a few grunts and pops out this beautiful baby in a lovely delivery, because it mostly isn't like that for your first baby. As soon as they see the reality that this isn't going to be over in a few minutes like on the television, they are so frightened. That's where I think we let people down. If we don't charge for classes, they're not valued and it's hard to keep them going. If we do charge, a whole lot of people can't afford them. But it is the expectations and the impression of what that's going to be like. Nobody has talked about it. Your mother-in-law has just told you to "be quiet" or "have a caesarean section". That's very much what our population does. It's going to go badly, isn't it, when you have that wrong impression.

SHEREE DIBIASE: Dr King, I just want to say—and I think the physiotherapist mentioned this—that the more integration of services that you have together, the better. I think that's why she was saying some of these hospital-based systems are so good—because what are you offering? In our system right now we have a birth collective where the pelvic PT and childbirth educator are part of it. We have a nutritionist and we have a mental health and a lactation consultant. They see all of those people before they labour and deliver, so they know where their floor is and they know what they're doing.

I want to say this: A physical therapist is literally a musculoskeletal expert. They know how the bones and muscles are supposed to move. Our participation with you as a physician is that we're working together with you, teaming, to make sure it never happens where you have somebody who doesn't even know where their floor is. We're pre-empting it by having a birth collective group that goes after them right from the start, and I think that changes it. I want to say that we don't want to normalise these people that have never looked at their floor before. We're trying to say, "No. We're going to enter in before," so that these people know where their floor is, and they know what to do so that it makes your life 10 times better and their life 10 times better afterwards. I think this is the beauty of physical therapists and physiotherapists in this space of women's health, prenatally and postpartum. We're going to have way better outcomes longer term, because now we have people who want to know and understand, and they don't want pelvic organ prolapses all over the world.

JENNY KING: Money.

The CHAIR: Based on what Sheree has just been saying, Ms Willis, in your submission, I note that you said that pelvic health physio is vastly underfunded in New South Wales compared to, say, Victoria. What Sheree is talking about sounds amazing. What are women missing out on in New South Wales and what are they getting in Victoria? Are they getting something similar to what Sheree is saying or is it not even as good as that there?

CATHERINE WILLIS: I can't really speak for what's happening in the United States but in other States that I am aware of—for example, Victoria and Queensland—we have reasonable funding for pelvic floor physiotherapy in the public sector. Again, I have to stress that this is particularly around your metropolitan areas and not necessarily rural. You have an ability for GPs, midwives or obstetricians to refer to physiotherapy. If a woman has attended an antenatal education class, we can self-refer them into our physio service as well, if there are screenings that lead us to be concerned about risk factors for that patient.

It means that there's more staffing and there's more available hours to see these patients during their pregnancy but also to be able to fit them in for their appointments after they've had their babies. I did want to address very quickly some of those other special populations that have been part of the hearing so far, including our LGBTIQ+ population, our Indigenous population, our CALD population and our younger women as well. When we think about the barriers to some of these groups attending antenatal education classes or appointments, we really have to look at some consumer co-design to make sure that we're able to provide them with the education at the right time, and in the right way, for that group.

The CHAIR: When you talk about some of those services in Victoria and Queensland, is there nothing like that in New South Wales?

JENNY KING: No. We have 5,000 deliveries a year. We have 1½ FTE physiotherapists for the women's health ward who have to do post-op patients, antenatal and postnatal. They have a bit of time for group classes. They are finding it desperately difficult to run any sort of outpatient thing. Our community health centres no longer have continence nurses or physiotherapists. All they have is someone to look after catheters. There is no service for public patients to get physiotherapy in the community. The waiting list to be seen in the public hospitals is 12 to 18 months. It's a disaster.

CATHERINE WILLIS: And attending private appointments is very prohibitive due to cost.

JENNY KING: I wasn't going to say anything about how much they charge.

CATHERINE WILLIS: We're worth it!

JENNY KING: Well, you are! There is a scheme—and you'd probably know better than I do—if you've got multiple other health conditions, you can have six visits to a physio. That works for my older ladies but it doesn't work for the younger ones. They haven't got six other conditions. It is dire.

CATHERINE WILLIS: What we're asking for, through the Australian Physiotherapy Association, is some kind of subsidy or increased staffing, increased funding for physiotherapy staff in the public health sector so that women do have access to at least one appointment during the antenatal period—and potentially up to four appointments postnatally with a pelvic floor physiotherapist.

The Hon. EMILY SUVAAL: Ms Willis, with the program that you're describing, is that funded for all of Victoria?

CATHERINE WILLIS: Sorry, I missed that word. "Parameter", did you say?

The Hon. EMILY SUVAAL: Is it publicly funded for all of Victoria, the program that you were describing earlier?

CATHERINE WILLIS: It's funded for predominantly hospitals in the Greater Melbourne area. I can't speak to every regional hospital in Victoria as well, but I know that the main hospitals in the Melbourne area do have this funding for physiotherapy but also the primary contact physiotherapy as well, which is what, for example, maybe some of your more chronic patients would then access.

The Hon. EMILY SUVAAL: Thank you for clarifying. My second question is to Dr King. Thanks so much for appearing today. In your opening statement you talked about the expectations that women have. I'd invite you to expand further on that and how the Committee can consider recommendations for this inquiry that will benefit the health system and, ultimately, women.

JENNY KING: It's hard, isn't it, because I'm old now and so I think everyone under about 30 is a wimp and has to have "me" time, which was never anything. I'm probably a little bit tough, but it's that whole thing of thinking you can control the birth process and it's a shock to the system when you can't. It's that attitude of, "Having this baby is not going to change how I live my life." I think, "Well, why are you having this baby?" But there's also that whole expectation that you'll be able to manage the situation. In fact, labour is a very cruel midwife, really.

You have to accept that unexpected things will happen, and if you know about them—what if you get to the stage where you've got terrible fetal distress and some doctor you've never laid eyes on before—this is part of the problem, that lack of continuity of care—comes in and says, "I'm going to have to help with this. Yes, it might be a bit uncomfortable. You're going to have a cut and you're going to be a bit more bruised than you thought." People are desperately disappointed. There's no concept that not everyone gets a nice normal delivery and that concept of the way I was trained: healthy baby, healthy mum. That's all we want out of the day—but it's not now. It's that feeling of, "It's about my experience." If your experience doesn't match to your expectations, which it very often won't, you're disappointed. I have trouble understanding that. I'm very glad I don't have to look after young women in obstetrics now.

SHEREE DIBIASE: Dr King, I just want to explain to you—

The Hon. EMILY SUVAAL: Sorry, if I can just continue—sorry to jump over the top of you, Sheree. I just have a follow-on question for Dr King around that. You talked about the issues that can present with having a baby in distress and someone you haven't met before who may have to make a decision quite quickly. This goes to some of the issues we've heard about in the inquiry—

JENNY KING: I've read them, yes.

The Hon. EMILY SUVAAL: —around informed consent. I invite to you make some comments on that. It's certainly an area that we as a committee would not be expert to make recommendations on, but I'm interested in some of the complexities involved with that and how we could manage that.

JENNY KING: I think we could often manage those situations better. But there is no way you can be fully prepared for everything that might happen. We can talk about forceps deliveries and what that might involve, and when we might want to do it or when we might want to go to theatre to have you there in case the forceps don't work and we need a caesarean. You can talk about those coolly and calmly beforehand, and that's fine if you've got private obstetric care. If you're in a clinic situation, there is no time. I know we're meant to talk about all of those things but it doesn't happen because there isn't time. We need to work out some sort of continuity of

care. Patients who are cared for by midwives have a much better outcome than someone who sees a very junior resident one week and might see a consultant once in the visit. It's awful, and I get why they're not happy and they don't feel that there's anyone they can ask.

The consent process is very different when you know your doctor. You go, "I've been seeing you for months. I trust you. I know you'll do what you have to do. Just get that baby out and have it in one piece." You don't really mind because you've got that trust—but not in the public system, you don't. Why should you trust them? You've never laid eyes on them. They look like they're 12-years-old. What would they know about anything? The whole system, honestly, it sets us up for problems. No-one gets the time they need or the care they need. It's get 'em in and get 'em out.

The Hon. EMILY SUVAAL: What can we do to improve that? Given we've obviously got to keep training junior doctors and there are obviously issues that are facing everyone in terms of costs, staffing, workforce and all of that sort of stuff, what are your thoughts around models of care and what we can do in that space to improve the experience that women have?

JENNY KING: It's probably worth putting your money into more midwives, not so much more doctors, because we really only need to step in when there's an issue. But if you could have enough midwives that you could pretty well do a group of five, who would look after 20 women for the pregnancy, it's going to be someone that you know, someone that you've seen, someone who can come in. Those models of care, along with some decent education, I think they would solve a lot of the problems. I know that's expensive if I say five more midwives, but it's not as expensive as unhappy mums who feel disappointed and damaged babies who didn't do well. That's \$20 million every time that happens. How many midwives can you pay with for that?

The Hon. EMILY SUVAAL: I suppose we've also heard evidence in this inquiry about not just the cost factor, obviously, but the workforce challenges and the issues that we face in terms of midwives and indeed physiotherapists, here in New South Wales particularly. Ms Willis, your submission talks about publicly funding obstetric pelvic health physiotherapy. Is there currently the workforce available? If we were to, in the perfect scenario, have the money and the means to be able to do that tomorrow, what are the workforce issues that we would face? Where are they going to come from?

CATHERINE WILLIS: I think that we could attract workforce who are currently working in the private sector. I can say from experience that a lot of the physiotherapists who are working in pelvic health physiotherapy are themselves part time with a young family. I think that if there was really good remuneration around working for the public sector, I think that you could access some of that workforce from private. When we look at some of the robust training schemes, whether it's the postgraduate qualifications through the universities or the Australian Physiotherapy Career Pathway, there are certainly goals where we could say, "Yes, we can put, in 2024, 250 more physiotherapists through this training pathway in New South Wales alone." Then you can build up that workforce fairly quickly and, with the physiotherapists who already have that experience, use them as supervisors or mentors to help with that workforce as well.

The Hon. EMILY SUVAAL: What you've both said has been very valuable, thank you. With the issue of time, which I know you mentioned, Dr King, which is always everyone's enemy and best friend, if it is the case that we've got limited time to provide information to women—because education obviously is a really key aspect that this inquiry has canvassed—what are the sorts of things that we can or should focus on in that antenatal period? Indeed, we've heard earlier evidence today about wanting more information earlier. How do we strike that balance, given everyone is different and everyone's education needs certainly are different?

JENNY KING: You could certainly, I think, make use of technology much better—and everyone knows more about that than I do. If you had a few more midwives, some of them could—look, they wait for hours out in that bloody antenatal clinic. You could be doing a lot of stuff in that time.

The Hon. EMILY SUVAAL: I know. I've sat there.

JENNY KING: It doesn't matter how efficient you try to get; it doesn't happen. We could certainly make use of that time better. I'm thinking some sort of whole introductory thing. You can look at your little video. You can sit there with your kids or someone who speaks English and say, "Okay, we're going to talk about this. What do you want to know about that?" That, they can look at at home and come prepared with some questions. Even that would be such a start—a little bit more what they're in for, without being scary. It is hard if it's only a youngster who speaks English in the house and the husbands just don't. A lot of them, they feel really embarrassed. So there's that that's an issue. But we could certainly work through our community groups much better than we do.

The Hon. EMILY SUVAAL: Community groups. Okay.

CATHERINE WILLIS: Again, I would back Jenny up with utilising technology. The Australasian Birth Trauma Association has been working with RANZCOG to put together some really amazing patient resources. I think something that's a really interesting analogy is think about how much it has changed in the last five to 10 years when you go to the bank. You no longer queue up, waiting to see a teller. You get greeted at the door by someone who asks you what you're here for today, and they might give you some pre-reading, and they might direct you to somewhere that's nice and lovely-looking so that you can sit down. So I think that we could do that with our waiting areas as well. We could have a midwife concierge who asks them if they have any particular things they would like to read while they're sitting there waiting. We could have audiovisual displays. We could have posters. There are so many things like that that we could be utilising to improve the experience for the consumers.

JENNY KING: It does need money, but—

SHEREE DIBIASE: Part of what happens in the US—and I just want to explain it like this, because it might help. We have over 40 per cent of our people that are on public health assistance that have babies. What ends up happening is now the US has incorporated doulas and midwives into the ability to have them as part of the birth plan. So that way a woman already has a plan, and she's exposed to the fact that maybe if she does have a C-section, this is what will happen and this is what will go on. Then they have the right with public assistance to actually have pre-natal care and 12 months of postpartum care through the public assistance program of Medicaid in the US.

They now are going to pay doulas to assist in that, and it's going to go state by state so that these doulas could prep and ready, because they're not as expensive as a midwife. But then they're going to incorporate all the steps of it, because we don't have enough OB/GYNs and we don't have enough nurse practitioners. So we now have to reach out and do the same thing you are. Literally, in our states we have maternal deserts where there are absolutely no OB/GYNs. So what happens is we are using telehealth to facilitate these people through the public health departments in different regions of the state so that those people then actually see their provider or whoever it is at that health department. But it's through a telehealth visit, and then their doula or their midwife who is more localised to them can help.

The CHAIR: Wonderful. Thank you so much for that. Thank you to all of you for giving your time today. We really appreciate that. If there were any questions taken on notice or if there are any questions from the Committee, the secretariat will be in contact.

(The witnesses withdrew.)

(Luncheon adjournment)

Ms JULIE BORNINKHOF, CEO, Perinatal Anxiety and Depression Australia [PANDA], affirmed and examined

Ms KAREN EDWARDS, Clinical Director, Gidget Foundation Australia, affirmed and examined

The CHAIR: Welcome back to our inquiry into birth trauma. I now welcome our next witnesses. Ms Edwards, did you have an opening statement you'd like to give?

KAREN EDWARDS: I did, thank you. Good afternoon. My name is Karen Edwards. I'm the clinical director of Gidget Foundation Australia. Gidget Foundation is a not-for-profit organisation that exists to support the emotional wellbeing of expectant and new parents through advocacy, education and service delivery to prevent and treat mental health issues. With one in three women describing their birth experience as traumatic, we know that birth trauma can significantly influence a parent's sense of wellbeing. An experience of birth trauma also increases a parent's risk of developing perinatal depression and anxiety, post-traumatic stress disorder or other mental illness. As a national provider of perinatal mental health services, Gidget Foundation Australia sees firsthand the importance of prevention, screening and early intervention in reducing the impact of birth trauma on the lives of women and their families across New South Wales.

Without treatment, birth trauma can significantly impact parents, their infants and the wider family, affecting parent-infant attachment, family relationships and feelings of self-worth as a parent and partner. Appropriate physical and psychological care is critical in reducing disruption to early attachment and in building parenting confidence and wellbeing. Informed choice can significantly reduce the impact of traumatic events and should sit at the centre of all maternity care. Women should be provided with a range of options aligned to their physical, emotional and cultural needs, and care should be decided collaboratively and without judgement. Access to sustained relationships with a single healthcare provider should also be improved, and health policy should expressly articulate that a birthing parent is entitled to make choices around their care, even when there are risks associated with that decision.

Finally, in seeking to improve the perinatal wellbeing of New South Wales women and their families, we acknowledge the need for critical changes in maternity care, particularly identifying the importance of education and training, adjustments to policies and procedures around genuine informed consent, and the development of models of care which focus on universal antenatal and post-natal screening, early intervention and improved access to wraparound service provision.

The CHAIR: Thank you. Ms Borninkhof, did you have an opening statement?

JULIE BORNINKHOF: In brief, I'd like to acknowledge the lived experience that has sat before this Committee and that I bring to this conversation as the leader of an organisation that was founded on lived experience. We believe that it is really important that people have choice in the care that they are provided and that we set people up for success, men and women, when we enter into the birthing experience. PANDA advocates broadly and has hundreds of thousands of connections with community through the digital resources and the helpline services that we provide.

We hear time and again that the real-life stories of people and their experience have helped in how people both prepare for, enter into birth and then become parents and support their children to become healthy adults in going forward. We know that the work that needs to be undertaken around birth trauma is one that—as PANDA, we see predominantly the mental health side of things. But we know that having integrated support that allows people to unpack their experience, regardless of the impact it had on them in the moment or longitudinally, is fundamentally important, and that we have no wrong door in terms of how we allow people to explore their mental health and their physical trauma.

It's a very personal thing, and at PANDA we understand that even a lack of somebody's ability to enact their birth plan or the expectations that they had in going into the birth can significantly set them up to feelings of failure as they become a new parent. So we reinforce the need for person-centred, evidence-based care that provides a continuum of approach and ensures that we're providing the most cost effective and accessible solutions to community that give them choice in accessing advocate digital resources at the front end through to specialised seamless services such as PANDAs that can hold people while they get community-centred services on the ground for ongoing psychological support. They are fundamental.

The CHAIR: Thank you both so much and thank you for all the work that you do. I am looking to Committee members to start off questions.

Dr AMANDA COHN: Sure. I am happy to start off. I have a very specific question for PANDA. First of all, thank you to both of you for being here today. We've had prior evidence to this inquiry from people that have

really valued PANDA as a service, and there were some comments around the fact that it was only available for the first 12 months after a new baby. First, I want to check that that is the case.

JULIE BORNINKHOF: It is the case. One of our contracts in another State is up to 24 months of age, but we've actually had to cap it because we can only ever get to a percentage of demand. Last week, as an example, we met 43 per cent of live demand to our helpline. The rest of the people reaching out for support had to leave messages and then we called them back within 24 to 48 hours.

Dr AMANDA COHN: I think you've mostly answered my follow-up question: For people who have trauma from a birthing experience that they've processed slowly and realised after that 12-month period, what are the barriers to PANDA being able to provide that? It sounds like it's just resourcing.

JULIE BORNINKHOF: Most definitely resourcing. We have an amazing digital system that is there and able to provide support, but it's the funding that we are given and the contracts and their stipulations that restrict how we provide care.

Dr AMANDA COHN: Do you have any of those contract restrictions in New South Wales currently?

JULIE BORNINKHOF: We only have one contract with New South Wales and that's a very small justice project that we're starting for women who are exiting correction facilities and who may be pregnant.

The Hon. SARAH MITCHELL: Thank you both for being here and for the work that you do. I'd just like to echo the comments of Dr Cohn. We've had some really positive feedback, particularly about PANDA, but I also know the work that Gidget does and how invaluable that is to a lot of families. Thank you for your expertise. I want to ask about something—and it was called out in the Gidget submission—that the Committee is grappling with in terms of what defines a traumatic birth. We've obviously spoken about the physical impacts that some women have and the emotional trauma. Some of that can be immediate; some may not be felt until some period afterwards. I guess in terms of your experience and expertise, how would you suggest we move forward in terms of what birth trauma is, how we define it and how we make recommendations around it? I appreciate that is a very difficult question to answer, but I am just keen for your insights.

KAREN EDWARDS: Where I think the solution to this lies is really in starting with the early screening piece and starting to understand women's experiences around how they feel about their birth. We tend to readily identify birth trauma where there has been some sort of high-risk obstetric intervention. Those ones are really easy to pick up. But because we know that birth trauma is an intersection of both the individual's personal experiences, the care journey they have—who provides their care—and then, I guess, the actual labour process and any of the risks that come up with that, it's really difficult to create a perfect map that knows how that's going to play out for women.

But what we do know is that when we screen women very early after they have had their baby, when we screen them after their baby's born, initially within a couple of days and then again, say, at six weeks, we start to be given indications of who is doing well and who feels comfortable or is happy with the way they're able to process their birth journey versus those who are starting to say, "I'm feeling really mixed emotions" or "I'm really struggling with my recollection of the birth journey and my experiences, and I'm not on the parenting trajectory that I expected to find myself on." I really think there is that piece. Yes, it's important to try and find a definition, but I think that definition really sits around how the experience impacts an individual. It is traumatic if it's causing distressing symptoms which affect their ability to transition into their parenting role confidently, comfortably and as the best version of themselves, given all of the other complexities that go on in and around that.

The Hon. SARAH MITCHELL: Did you want to add anything?

JULIE BORNINKHOF: Yes. I would add that we have a checklist that sits on our website. We've had over 200,000 completions. It's completed by an international audience. But we know that when we look into our New South Wales data, as an example, 54 per cent of mums and 46 or 47 per cent of dads are upset ongoing and significantly by the experience of their birth. Again, they may not meet clinical diagnostic criteria, but it is enough to disrupt both their attachment and their connection with their bub but also the identity that they form as parents—either new or second or third time around—as they move into that role. We know that if we don't address the identity that parents have and the comfort that they feel with that identity, then the ongoing impacts on their mental health and wellbeing will be exacerbated. It's person centred, somebody's impact of experience of trauma around the birth, but it's also where we, as a system, want to meet people's needs. Do we want to be meeting them at a higher end, a more costly part of the health system, or do we want to be providing them with support that is easily accessible earlier on? It's all fluid in many ways.

The Hon. SARAH MITCHELL: The other thing that you've both called out in your submissions in terms of recommendations is training to maternity healthcare providers around trauma-informed care. It will probably

please you but not surprise you to know that's also come up from other submissions, which I think is good. Consistency is good for the Committee to know what everybody agrees is a good way forward. One of the things that we've heard, particularly from those that have lived experience, is that sometimes it just might depend on the healthcare provider that you've got that day. Others saw a more sustained pattern of behaviour in the hospitals, for instance, where they were. In terms of what further or better training could be provided for those healthcare professionals—and understanding that they're often in a very stressful work environment as well, so it's complex—is there anywhere that you think there are gaps currently in terms of that trauma-informed care that we could make recommendations around, particularly for the training for midwives and doctors and the like?

JULIE BORNINKHOF: We find that training is so important, and accessible training often delivered by multiple agencies and approaches is really fundamental because people get their skill set reaffirmed over time by up-taking different training methodologies. We do know that for certain health professional groups, such as primary care providers and GPs, short sharp training is enough to expose them to the skill set that allows them to feel a little bit more confident in opening up those conversations.

But what we know at PANDA from the health professionals that we train broadly—more in Victoria where we have State funding to do so—that the secondary consultation part of what we deliver as a national organisation through Commonwealth funding and Victorian funding is really important so that we can give people the skill set to be able to have conversations with those that they're sitting with, to unpack experience, to delve into those things. But sometimes health professionals need to undertake secondary consultation, either while they're with that patient or after that to be able to comprehend whether or not what they did in that moment was useful, whether it was appropriate and to learn. Often that application and follow-up of a care stream, like a secondary consultation, is fundamental in being able to embed practice.

KAREN EDWARDS: I think one of the things that's really important is understanding that you need to empower health professionals to, one, undertake the training and then feel that they're okay to work to the top of their scope of practice based on that training—so, helping all health professionals understand how to unpack the information they receive. Because one of the challenges for a parent is that the health professional you're presenting to might not be the one with expertise in the area where you need help.

The training really has to focus on making sure that we have all health professionals across maternity care much better able to identify risk and to be able to identify whether it's physical risk, it's psychological risk so that they're able to, one, unpack that a little more and factor that into the way that they work with the person in front of them but, two, refer appropriately. I think the training really has to be focused on helping all professionals work at the top of their scope so that we're able to get some of those efficiencies and some of that no-wrong-door that Julie's spoken about where the person that you speak to, whether it's your GP, your midwife, your obstetrician or a mental health clinician that you've been referred to, is able to start to point you in the right direction and start to help you understand what's happening for you and what the way forward looks like.

The Hon. SARAH MITCHELL: I have one more question, which is kind of specific but then more general. In the Gidget submission you call out the need for women who have experienced recent loss not to be in a shared space with other mothers and babies. We've heard that a few times, and I think it's an excellent recommendation because it's obviously very traumatic when you find yourself in that experience. But you also talked about recognising the trauma of the non-birthing parent, the support person or partner, and, when we talk about that education piece, the role for that partner or support person to be included in that. I am not going to ask why it is a good idea to have separate spaces, because it just is. I think we all agree with that. But in terms of calling out the support person, their trauma and their role in being informed in a way that they can help their partner have a voice in a birthing experience that maybe isn't going to plan, how important do you think that is and, again, are there any recommendations for improving that system?

KAREN EDWARDS: I think it is making sure that both birthing and non-birthing parents have access to the right support at that earliest opportunity. We can't stress enough the importance of early intervention. So much, particularly following a grief or loss, is often very focused on physical outcomes, physical processes and physical support, but there is a massive psychological piece in there that can significantly influence how the parent goes on to adjust to all of the traumatic events that they've just experienced and then goes on to process their grief and loss. From our perspective, it's making sure that the care provided at that point in time has due consideration for the psychological needs of both parents and makes that available in a timely and efficient way.

The Hon. SARAH MITCHELL: Do you want to add anything, Julie?

JULIE BORNINKHOF: I agree, and I think, from the men that we speak to on the helpline, it's reinforced time and time again that not only do they need that debrief and that capacity to get support immediately following the birth but also within the birthing suite when they're not only watching their partner go through this but they're completely traumatised and often pushed to the side. I think we can do better in that space also.

The CHAIR: I might jump in with a couple of questions myself. Within your submissions you both flagged the lack of informed consent as being an issue when it comes to birth trauma. Is that something that women have often flagged with you when they are talking about cases of birth trauma? Can you expand a little bit more on that? That question is for both of you.

JULIE BORNINKHOF: I'll jump in. We often hear from callers to the helpline, both as a result of birth trauma but general psychological wellbeing, that they weren't given the choice in the moment to adjust to or respond to something that they were presented with, and that is an ongoing issue. We know that birthing processes can be very high paced and high demand, and it's not always possible to, but we also think that we set people up for failure as they are in their pregnancy phase and nearing the birthing journey, because we always assume and promote—many services promote to people that they have choice and that they can set up a birth plan and do all these things, and we don't allow people the space to understand that birthing is a complex space and that many things do not necessarily go wrong but are at play when somebody is having a baby. We believe that advocacy, stories and information around what the birthing experience is and looks like—in many languages—needs to be there. We need to focus in on information about—there are going to be times when decisions need to be made but, in the best practice, we want to be informing consent for any procedure at any time.

KAREN EDWARDS: I would just add that it is important to understand that you don't have genuine informed consent if someone is not apprised of all the options available to them. Sometimes women will technically consent to a procedure or a process but without adequate understanding of what their alternatives might have been and what are the risks associated with either choice. That's a really interesting piece for us—to think about whether the risk decision sits with the woman or the birthing parent or whether the risk decision ultimately sits with the clinician. What we see is that sometimes women aren't given a sufficient say in being able to assess and evaluate the risks that are inherent in each choice and to make a decision with a full suite of information or as full as possible, given that sometimes there is a pressing urgency. From our perspective, that idea that there needs to be greater communication with women around their options and around the pros and cons of each option is an important part of the informed consent along with getting the "Yes, I agree".

The CHAIR: I know that you raised a specific concern about policies which favour early discharge over informed consent. Can you expand on that?

KAREN EDWARDS: What I was really referring to there is that we actually speak to a lot of women who would have liked to have stayed in hospital longer and would have liked to have had a little more time to adjust to some of the physical changes that they've perhaps been through, particularly women who have had a traumatic birth, to have a little more oversight of their physical symptoms and a little bit more reassurance that things were progressing normally, but they have been discharged because that is the hospital policy. They've been declared well enough to go home, and that means you go home as opposed to saying, when we look at the whole person, they might be physically capable of managing this condition at home, but when we factor in their psychological wellbeing and their readiness to cope with this physical issue at home along with the entire transition to parenthood, they don't feel ready and they need more support, and they need to be heard around that.

The CHAIR: Absolutely. We have heard at some points during this inquiry that requiring informed consent is not a good idea because decisions need to be made in emergency situations. Is there a way around dealing with that so that where there is an emergency situation there is still informed consent? Is there a difference between that sort of early-stage informed consent and on-the-spot informed consent, and can we do both?

KAREN EDWARDS: I think it represents a challenge. I recognise that it is not a perfect line that we're going to be able to walk in every scenario. I think, firstly—having realistic conversations with women well before this point in time around what their options are and what kind of events might trigger a cascade through those options. I don't think there is enough work done in some areas to make sure women are fully across the circumstances that might lead to them needing to go down particular obstetric paths. I think that early conversation is one place to start to get informed consent because you're able to provide that information element. That means there's a much clearer element of this "yes" is meaningful. I think it also gives women time to think about and ponder what their options are and where they might land so they are much better prepared should things happen quite quickly beyond that. That's the first thing.

The second thing is what we know from the research is that people who work consistently with a single healthcare provider actually tend to have less traumatic experiences and feel that that informed consent was more appropriately obtained, and I think that speaks to the way people communicate and that trust piece that goes on. It is a communication. The informed consent comes from providing the information and the person being in a position to feel this person knows me and understands me and is helping me evaluate my circumstances with a very person-centred lens and not an organisational lens, an expediency lens or any of those other things. I think that will improve our informed consent, if we look at that piece, because I think the relationship builds much more

reciprocal communication. The other thing is that we do need, where possible, to get all healthcare providers to stop, pause and take the time to have a clear conversation wherever they can.

JULIE BORNINKHOF: Can I add that, again, how we set people up, the information we provide, and the language that we wrap around what to expect from a birth experience is really important in this space. It's important that we use plain English and that we don't use jargon. We hear constantly from callers to the helpline—again, around broader things than just birth trauma—that they didn't understand the terminology being used. They felt that it was spoken in a way that was inconsistent with their experience and their ability to comprehend that information. So, again, we need to bring it down. We need to be clear about what it is we're discussing, not using acronyms and using plain English. And we need to be using that information from the very beginning so that people are going into the hospital experience or homebirth experience understanding what this means prior to getting there.

The CHAIR: I have another question for both of you. Obviously the services you both provide are critical services that support women who may be suffering with trauma. What would you need to expand these services further? Is it funding? Is it other things around awareness of those services so women know to reach out to you? Or are there other aspects that need to take place?

JULIE BORNINKHOF: As we put forward, we think it's really important that people have access to a range of services, and we believe that services like PANDA can provide the safety net as people transition either into birthing or out of having their bubs. We understand the importance of localised, community-based services and services that are integrated with more holistic care communities. But, ultimately, we know at PANDA that we cannot meet demand for our current callers. At the moment, 10.4 per cent of our callers from New South Wales identify birth trauma as a reason for coming to our service, but when we unpack conversations with people who don't identify birth trauma as the reason for calling, so many people have this experience.

We know that we need to provide specialist care, and we don't think that specialised care for any state or trait can sit within generalised services. That's why we have put forward a proposal that harnesses the expertise of amazing organisations like the Australasian Birth Trauma Association, which can bring forward lived experience as a treatment methodology to provide care to people early on and which sits as that safety net for people as they navigate the system, whether it is getting care for their physical trauma or their psychological trauma. PANDA loves to partner. As an organisation, partnership really important. We need to be able to refer to partner organisations such as Gidget House and other specialty providers. We need to be connected to the physical responders as well, once we've provided that initial care.

KAREN EDWARDS: From our perspective, as Julie has already spoken to, our growth in demand continues to grow annually. It really does require ongoing growth in resources to continue to meet that demand. There are a couple of things that we think are really significant around providing the support that women need in the way that women need it. One of those is around how we look at what the barriers are to moving across and between services. We know that, for example, to access the Medicare bulk-billed services that Gidget House provides, a midwife who is well positioned to assess the need for mental health care must send that person back to their GP for the mental health plan. PANDA can identify callers and they must go back through the GP. Obstetricians can identify mental health presentations that must go back through the GP for the referral to be eligible for those Medicare services. Those sorts of things create an accessibility barrier. Looking at ways that we can facilitate onward referral between health services, and between public, private and not-for-profit systems, is really important.

The other element of that is around looking at how so many of our models of care are not well set up and evidence based in terms of the duration of the treatment that we allow people to access under a bulk-billed or funded model. To expect that someone who, perhaps, can't afford private services might get the resolution they need in 10 sessions—there will certainly be women who 10 sessions will be more than adequate for, but we know that there are other, complex presentations, particularly when there has been birth trauma, where 10 sessions is not adequate. Being able to offer an extended service is something that's really important—saying that we're going to do a piece of work around treatment rather than some of the bandaiding that women are often forced to accept because their financial resources don't give them the choices otherwise.

The Hon. SUSAN CARTER: Thank you both for being here, and apologies I was a bit late. I am interested in the issue around consent and the time at which women need to receive the information, the context and the language. It has been put to us in other testimony by other witnesses that we can over-inform in the sense that we can raise anxiety in women if we inform them about procedures or complications that then aren't necessary for them. Yet, if we don't provide that information, women find themselves sometimes with literally seconds to make significant decisions about their baby's health and their own health. Do you have any thoughts about how we manage this tension or is it just one of those things that we have to deal with on a case-by-case basis?

KAREN EDWARDS: I certainly think managing the language we use when we talk about things to be really clear about what is likely and what is unlikely—those sorts of things are really important. We don't want to introduce a range of options so that many women think they've got a four-way even chance of any one of the four happening. I think it's really important that we're clear around what is most likely versus what is less likely. But it's also about making sure that we do talk about those things, as Julie has alluded to, in very plain English so that people can understand and ask the questions they need to ask.

One of the things that can be quite traumatising is having a half-informed view of what might happen in a process where you don't get your questions answered and you don't get to understand the risk that is associated or not associated with that. That becomes a really important element of making sure that we're able to provide information but not escalate anxiety, by having a two-way conversation. It's not about just handing out literature and saying, "Here's all the things you need to know about your birth." We know that having that conversation with a trusted healthcare provider can really help manage and contain that anxiety and help put it into a context that is relevant to the individual and their presentation.

The Hon. SUSAN CARTER: We've also had evidence that women don't turn up for scheduled prenatal education. I wonder whether that's even more likely in second and third pregnancies than in the first. How do we inform women or ensure that they're consenting if they're not prioritising educating themselves about these issues?

KAREN EDWARDS: I do think that's a challenge. One of the things that we need to do, again, is to think about what our opportunities are. If we come back to our education around making sure that all healthcare providers who might encounter a woman on her pregnancy or postpartum journey are well informed, we create a lot more opportunities for that. It might be the GP when you turn up with your five-year-old who needs a routine vaccination. It might be the midwife who you see as you're booking into the hospital. We need to look for opportunities to have conversations and to make sure our healthcare workforce is suitably resourced to have those conversations at the appropriate time and to do that opportunistically.

The Hon. SUSAN CARTER: There are two issues that arise for me out of what you've just said—appropriately resourced. We've heard a number of submissions about pressure on GPs, pressure on midwives and pressures of time. The other is, if we're seeing it as taking the opportunities, how are we ever sure that each woman has been completely exposed to everything that she needs to know and understand about her pregnancy and her birth?

KAREN EDWARDS: These are wicked problems, and they don't have easy solutions. It's probably an impossibility to ensure that every woman has had every opportunity when we're talking about people who have not presented for any routine antenatal care.

The Hon. SUSAN CARTER: But how do we then deal with the consent piece?

KAREN EDWARDS: I think the first part of it is to make sure that we deliver this as broadly and widely as we can, because that does improve our genuine consent and reduce the number of women placed in a position where they mightn't be able to. However, I think then we also perhaps look at, when someone does check in or present, trying to, as part of that admission process, get a really good understanding of what information they have been given or received to date and where there might be gaps in their knowledge or understanding and what it might be helpful to provide them with as part of that admission process.

The Hon. SUSAN CARTER: With the midwife at intake—or where does that check-in take place?

KAREN EDWARDS: That's outside my area of expertise, around when someone might have a conversation in a hospital. But that is where we would be advocating, is that at the earliest opportunity there is a discussion to understand what the woman's risk factors are. What are her presenting risk factors around her mental health? What are her presenting risk factors around her physical health, and what do we need to know and understand about what she understands about those and how we can best support her with that?

The Hon. SUSAN CARTER: Would you be in favour of an established curriculum or is it a person-by-person discussion?

KAREN EDWARDS: Is this for the healthcare workers?

The Hon. SUSAN CARTER: No, for what women should know. For example, should there be a New South Wales standard that says, "Every woman should have these 10 things discussed with her before she gives birth"? Or should it be asking, at check-in, "What's your level of understanding? What questions do you have?"

KAREN EDWARDS: It's probably a bit of both in that I do think we can never simplify a constructive health interaction down to just following a checklist, and part of what we ask of our healthcare professionals is

that they use their clinical judgement to work their way through a list of, I guess, key areas and that their questions are informed by who is in front of them—that there is a person-centred lens on how they approach that. I would say it's probably a bit of both and there would be, again, people working in that space who would be far better equipped to say exactly what that looked like. But from our perspective around the mental health element, we would like for midwives, obstetricians and people providing maternity care generally to have a much better understanding of the role of psychosocial risk factors in the development of birth trauma, and how understanding these and perhaps managing these can have a preventative effect in the escalation of traumatic symptoms.

JULIE BORNINKHOF: Can I just reinforce that I think that it is multifactorial, and I think that no one thing will do everything for an individual, whether you're a healthcare provider or a consumer. I think what's really important in the informed consent piece is that we're actually asking people what information they want to receive, because you will get some people who say, "Just do the best care to me," and some people will say, "No, I need to understand options." If we deliver beautiful, person-centred care, we're always asking the individual how they want to receive information and in what language they want to receive information and whether they want follow-up in the event that something should happen. I think too, as we've said before, setting people up for success in giving them realistic information about birth experience and what supports are there for them in the event that they don't have that birth experience, and that's given to people pre and post their birth in as many different ways as possible, needs to be encouraged.

The Hon. GREG DONNELLY: Thank you both for coming along this afternoon and providing us an opportunity to ask some questions to your very good submissions. You've shared so much this afternoon which has been excellent and, in fact, reflects statements and observations and, dare I say, recommendations that many others have made. The one thing that challenges me, and others can speak for themselves, is trying to identify with some specificity the resourcing gaps. Perhaps if I explain it this way, it might assist. Let's assume, hypothetically, we could wake up tomorrow and all these matters about the way the existing workforce goes about its engagements with pregnant women, right through to birthing and a period after birth, in a much better and more sophisticated way, in other words, nuanced, person-centred and all those things that you've said, is able to be achieved, from the obstetrician, the gynaecologist, right down to the person who might attend to the room and clean and tidy the room.

Let's assume we could get all of that magically right—which is, obviously, hypothetical. I don't think, from what I've heard from witnesses over this inquiry, that that in itself, if you could do that, would be enough, because there are, dare I say, manifest gaps out there which require some real resources to go in. And of course, there is debate and argument about where those gaps are and how much resources could go in. But I don't think there would be a debate that there are deficiencies in resources to address this, if we're serious. So the question becomes: Is there any sense of what that resource gap is? Because if there is a gap there—and I know this sounds hypothetical but, at the end of the day, there will be a requirement for the State to purchase what's required to achieve the outcome, so, in large measure, I would presume that does involve people to undertake the work still required. How do we grasp what that might be and is there a way in which we can calculate how we can transition up to that? Clearly, this cannot be done overnight. I know that sounds a bit obtuse, but there is the gap, we understand. Can we quantify that in some fashion and how do we move to filling that gap?

KAREN EDWARDS: My maths probably won't quantify it, but the way that I would like to think about it, that I think points us in the right direction, is I have significant concern over what I would consider to sometimes to be the postcode lottery around the quality of care you receive and the access to care and the wraparound care that goes with that. If we were to look somewhere towards what we consider to be our best case care—women who are well resourced through the range of services that are immediately available in and around them, through access to the healthcare professionals that support them, their access to allied health and other support care like physiotherapy, psychology is not limited by the dollar—I think when we look at what those well-resourced women are able to access and use, we go to some way towards understanding what we should be looking to replicate for women whose circumstances are less optimal, who live in country towns, women who live in less-resourced parts of Sydney and on the outskirts of Sydney and have far less resourcing, women on low incomes, women from marginalised community groups, CALD women et cetera.

I think if we could do some work towards saying, "How can we close that gap a little bit and how can we replicate some of the services that we know we're doing really well in some privileged postcodes?", we would have a little bit of a blueprint for how we could move forward in improving this for a big number of women across the State.

JULIE BORNINKHOF: It's a big question. I also think a lot of it's about what you already have and what you leverage. One of the things that I'm a staunch advocate for is that we don't replicate services and that we don't continue to fund new activity when existing activity is there. I think that taxpayer dollars, it is really important that that is leveraged and used as best it can. Our submission was based on how we value add to an

existing infrastructure, that we just have to scale-up a user licence for a clinician, as an example, coming onto that, and that is because we're able to leverage what taxpayers have already invested, across this country, into our service structure. I think that if we can continue to overlay into what is already there, what is trusted and build the brand of organisations—because a lot of accessibility barriers are around people not knowing about which pathway to tread or where to turn for care.

I think in building up organisations like the Australasian Birth Trauma Association, like PANDA—those that already exist and that have a brand and that people trust—we can go a long way to getting those services on the ground quicker, which means efficiencies of scale, efficiencies of funding. I agree, mapping out what good quality care looks like is a luxury but something that we don't often do and ensuring that we understand that there are discrete differences, especially around communities where English is a second language, or our Aboriginal and Torres Strait Islander communities, around homeless families that we're seeing more and more of, especially in Victoria and no doubt Sydney. I think they become more complex funding paradigms, but ultimately I think that as long as we're leveraging and not rebuilding, that's a really important efficiency.

The Hon. GREG DONNELLY: The "privileged postcodes"—I understand that phrase. Would it not be the case that the privilege in some of these postcodes is because there is resource capacity to purchase private health insurance and that enables quite a lot? But if we take those outside of the equation for the purposes of discussion, those postcodes where our public health system does it to a recognised standard, which is, dare I say it, not always 100 per cent but a broad consensus that it's being done pretty well or to a pretty high standard, how are they identified? Because if they are doing it well and we wish to sort of, dare I say, extend that good model of doing it broadly across the public health system, how do we identify those particular parts of the public health system that do it? I'm talking specifically about hospitals I suppose.

KAREN EDWARDS: Have you got anything springing to mind?

JULIE BORNINKHOF: I think ultimately it has to be done through community consultation. You've heard so many voices here. The best models of care are done through community consultation and they do relate to geographical overlays and communities of need and service structures, because I also think that you can have a wonderful tertiary health system in a space but then the primary health system that sits below that or wraps around it can be lacking. I think community consultation is needed to be able to understand what works within a space, and then what is needed to fill those gaps using a bit of a smorgasbord of what you've heard here around what key components need to be there to address families' wellbeing through this space.

KAREN EDWARDS: I'd agreed with that. I think that's really sensible. I guess the other thing is that it is really around that collaborative piece within and across organisations. I'm sure not just from the women whose birthing experiences you've spoken to but from the organisations that you will speak to over the course of these hearings as well. What you'll see is a lot of consistency around what we all recognise as good care and a lot of consistency around the elements of that care that's being delivered well by certain organisations and according to certain models of care and referral pathways.

I think that, again, having some collaborative consultation not just with community aspects of the service users but also with the service providers is the other half of that equation. I think there is an incredible amount of goodwill between organisations working in this space and a genuine desire to improve outcomes for women that sees organisations wanting to identify strengths and wanting to recognise those strengths and wanting to replicate those strengths. I think there's a big piece to be done within the sector through some collaborative work across the organisations.

The Hon. ANTHONY D'ADAM: Both your submissions make suggestions around screening for trauma. I wonder if you could perhaps elaborate on some of the issues associated with how we might put that into practice.

KAREN EDWARDS: I think the first thing around screening for trauma and putting that into practice is, again, the education piece around helping healthcare professionals understand why this is an important piece of the work they do. It's really important to have those educational pieces that help people link the psychological psychosocial risk factors with not only the implications for psychological wellbeing but also actually the risk factors around physical health that go with some of those psychosocial risk factors as well. Certainly, I think the first piece is the education piece for healthcare professionals, because if you don't have a workforce that understands the value of the screening piece and you don't have a workforce that is confident around why they might be doing this particular activity and where they're hoping to head with that, then I think it becomes just another tick-the-box that in a sort of very, very regulated kind of society feels like it's a lot more hard work than gain. So it really is getting that buy-in piece and that educational piece with healthcare professionals.

I think the second part is then giving healthcare professionals the skills to know what to do with the information they receive, so helping with that translational piece around, "If I understand these factors around a

woman's psychosocial risk profile, what kinds of steps should I take in providing physical care to this woman that will help address some of those psychological risk factors?" So what that might look like is in terms of any aspect of the care, from how the room is set up to who's present in the room, to how the conversations are conducted, to at what points in time you check in with someone and what that looks like around how you check in with them, understanding their preferred ways of being treated et cetera, and then starting to provide people with the skills that they can take this forward and understand what this information looks like in terms of the actualities of their clinical practice.

Then, ultimately, I think it's really, really important for healthcare professionals to receive feedback around how things are working. I think that's a really reinforcing process when as a healthcare professional you're able to see that the areas that you are working with a person on and the way you respond to them is impacting their healthcare outcomes and impacting their own perception of their care and of the quality of care that they've received.

JULIE BORNINKHOF: I would add that I think screening is so fundamentally important but we don't want screening to become a barrier to people engaging with their experience generally within the system. So I think we need to be mindful of ensuring we don't keep just adding to screening measures that are formal. I also think that some people, whether they're the deliverers of screening or the completers of screening, will not always engage with those pieces. So we need to set up safety nets and things like birth debriefs—the really important things that allow people to be autonomous and advocate for themselves in the event they didn't get the experience, and that people are made aware of that as quickly as possible.

At PANDA we advocate for screening as a fundamental. But we know that the system is fatigued, the workforce doesn't always have those opportunities or may have their own experience of birth trauma or psychological trauma and are working in a really high-pressured environment. As long as we're setting up things to sit within the gaps and ensure that, again, we have those multi-factorial approaches that provide care and provide people to get support—if they themselves self-screen as opposed to having a physical or a clinical screen within the facility.

The CHAIR: We have a couple of minutes left. Is there anything that you wanted to also raise with the Committee that we haven't asked in a question today that you felt needed to be covered or aired?

KAREN EDWARDS: I'd just really like to thank the Committee for their time and investment in trying to understand the experiences of women in New South Wales and looking for genuine ways forward to improve that experience for women over time and for the breadth of their consultation in trying to understand some very challenging issues in this space.

JULIE BORNINKHOF: As a CEO of a national organisation, I think New South Wales is most definitely leading the charge in opening up this conversation and having what is a really thorough process. Again, I think that whatever comes out of these sessions and the recommendations that follow really need to be recommendations that are person centred and are holistic and that don't become barriers to the delivery of care or the receiving of care. We know that humans are humans regardless of whether they're birthing or supporting people to birth, and we want to set up as much of a system that is supporting and complementing and able to wrap around people at any stage.

The CHAIR: Wonderful. Thank you both so much for coming today and providing your evidence. If any questions were taken on notice or if the Committee members think of any questions later, the secretariat will be in contact with you.

(The witnesses withdrew.)

Ms KATELYN COMMERFORD, President, Homebirth NSW, sworn and examined

Dr AIMEE SING, Vice-President, Homebirth NSW, affirmed and examined

Ms KRISTYN BEGNELL, Coordinator, Homebirth Australia, on former affirmation

Ms VIRGINIA MADDOCK, Assistant Coordinator, Homebirth Australia, sworn and examined

The CHAIR: I now welcome our next witnesses. Thank you all for joining us. Does a representative of Homebirth NSW have an opening statement?

AIMEE SING: We're here representing Homebirth NSW, a grassroots volunteer consumer representative organisation of over 40 years. We'd like to acknowledge and pay our respects to the traditional custodians of the land on which we meet today, the Gadigal people of the Eora nation, and pay our respects to Elders past, present and emerging. We've seen and heard in our community and the research how homebirth both prevents birth trauma and contributes to healing from it. Many women in our community choose homebirth, motivated by a desire to avoid trauma. We thank the Select Committee and all of the thousands of women who've shared their stories and provided submissions to this inquiry. We're both grateful to the Select Committee for the opportunity to openly discuss the birth trauma epidemic and completely dumbfounded by this hearing's necessity when the answers are so startlingly obvious to us.

Homebirth is neither a new idea nor a fad, but the way that women have birthed for the majority of human history. The safety of homebirth with a privately practising midwife—a PPM—has been well established in the literature, as has the cost saving to the health system. Unfortunately, homebirth is not an option that all women can access, due to location, PPM availability or finances. Intrapartum PPM care is not Medicare rebatable for homebirth so, even with antenatal and postnatal care rebates, families are left thousands out of pocket.

This results in homebirth being a privilege afforded primarily to white middle class women and those who are low risk, and it excludes those who are at greatest risk of trauma. Additionally, most women aren't made aware of homebirth or privately practising midwives and are instead funnelled into the hospital system when they first visit their GP, the maternity care gatekeepers. To access Medicare rebates for antenatal and postnatal privately practising midwifery care, women must obtain a referral from a GP. Yet GPs frequently refuse, either under instruction from their insurers or due to their own medical bias.

The midwives providing this gold standard of maternity care are some of our most skilled, educated and committed midwives, undertaking 5,000 hours of care, additional postgraduate and CPD studies to obtain endorsement and maintain skills, with no supportive pathways provided into this profession. Despite this, PPMs are expected to be overseen by GPs or OBs via mandated collaboration, still find themselves risking their registration to vexatious reporting and, due to the Government's unwillingness to find a solution to a 14-year-old professional indemnity insurance problem, risk their livelihoods every time they attend a homebirth as well.

KATELYN COMMERFORD: While homebirth substantially reduces the risk of birth trauma, it seems these benefits are abrogated when a transfer to hospital is required. Women frequently report coercion, mistreatment and even abuse after transferring. This issue could be eliminated in a heartbeat with true collaboration, where private midwives are respected and trusted as the autonomous and competent professionals that they are and where transfer pathways are created and respected by all involved.

Both the literature and women have been telling us the answer to the birth trauma epidemic for years now: continuity of midwifery carer. We also need to see support for midwives to practise to their full scope; support for culturally safe care, including birthing on country for our First Nations women; providing out-of-hospital birth options for all who want it; dismantling GP referral as the key to Medicare rebatable care; eradicating mandated collaboration in favour of true collaborative care; and providing supportive pathways for midwives seeking to enter and remain in private midwifery.

It's not the aesthetic of the home environment that is protecting women from poor outcomes and birth trauma in homebirth settings but rather the provision of relationship-based, individualised continuity of midwifery care—being treated with respect, acknowledgement of autonomy and informed consent throughout pregnancy, birth and postpartum. A birth unit can be made to look as much like a bedroom as you want but, without providing these crucial components of care that make the difference and that the system should be able to provide, it's ostentatious gaslighting and a waste of budget money. Midwives are the experts in physiological birth, and women are the experts in their own bodies and babies. It's time we respected that at a system level.

The CHAIR: Thank you. Is there an opening statement from Homebirth Australia?

KRISTYN BEGNELL: Thanks again to the Committee for the opportunity to present at today's inquiry. We'd also like to begin by acknowledging the traditional owners of the land on which we meet today, the Gadigal people of the Eora nation, and pay our respects to Elders past and present. Homebirth Australia is the national body for homebirth in Australia, with a 45-year history and 300 members, 45 per cent of which are midwives, 16 per cent consumers, and the other 40 per cent birth workers.

Birth is not an injury or an illness. When a woman feels safe, supported and unobserved, she is perfectly capable of giving birth to her baby without medical intervention the majority of the time. Yet birth has been pathologised and monetised by our health system. The safety of homebirth is continually brought into question in the media, despite the evidence being clear that homebirth is as safe for low-risk women and babies as hospital birth. As stated in the Human Rights in Childbirth submission to this inquiry, attacks on homebirth or other models of care are a convenient distraction from the real issue—the obstetric violence women face in facility-based care.

As Professor Hannah Dahlen stated on day one of this inquiry, homebirth with a midwife has the lowest rates of intervention and the lowest rates of birth trauma. So many women in New South Wales endure unnecessary trauma from birthing in a fragmented hospital system. We've heard some testimonies during this inquiry offering bandaied solutions to the issue of birth trauma, but we've also heard about the best preventative tool we have at our disposal: continuity of midwifery carer. Our health system does not trust midwives, and it does not trust women. Midwives are unable to practise to their full scope, and particularly midwives in private practice have numerous barriers in their way, which we would be happy to share in more detail during questioning.

The demand for homebirth far exceeds the supply, with PPMs often having to turn down multiple women every month. Australia currently has 18 publicly funded homebirth programs, six of those in New South Wales. Typically, these programs are not advertised to women who book into the hospital system. It is often a matter of women needing to know about the program before they fall pregnant, which is a privilege not afforded to women with language barriers or those who don't know how the system operates.

The programs we do have in New South Wales are not operating to their full capacity. This mirrors the issues we see with the reduction of MGP programs across the State. Midwives want to work in continuity models, but these models are often poorly managed, resulting in burnout or the programs being closed down. Publicly funded programs are also incredibly restrictive to women, potentially ruling out up to 60 per cent of the women who would want to access them.

Research suggests that homebirth has a positive impact on midwives as well. A 2020 study of the hospital-based midwives' experiences of providing publicly funded homebirth in Australia showed that witnessing undisturbed birth in the home setting transformed midwives' attitudes towards birth. Following exposure to homebirths, many midwives felt they were seeing undisturbed birth for the first time. This led them to question their current understanding of physiological birth and develop a new awareness of the powerful influence that the environment has on labouring women. This new understanding resulted in changes to their practice.

VIRGINIA MADDOCK: With respect, I'm just going to pause until I have the undivided attention of everybody on the Committee, please, because I am representing the voices of thousands of women, and I want them to know that they are heard.

The CHAIR: Mr Donnelly?

The Hon. GREG DONNELLY: I'm listening.

VIRGINIA MADDOCK: I've been a doula since 2006, gave birth to two babies at home and have been a volunteer homebirth advocate since the birth of my first-born 15 years ago, firstly with Homebirth NSW and now with Homebirth Australia. As a doula, I have supported 113 births, 49—or 43 per cent—of which were planned homebirths. Not all of these resulted in babies being born at home, so I have firsthand experience witnessing what can happen during a homebirth transfer, which is what I'm going to be talking about today.

Women who choose homebirth deserve access to safe and respectful hospital care in the event that it is wanted or needed. Some women who plan to homebirth might transfer to hospital during pregnancy due to unexpected medical conditions, transfer during labour—which is most often due to non-emergency reasons such as lack of progress or need for pain relief—or after birth due to additional medical assistance. Unfortunately, women's experiences of homebirth transfer are often traumatic because of the way they and their midwives are treated by hospital staff when they arrive. Estimates show that up to 50 per cent of privately practising midwives in New South Wales—and, indeed, probably around Australia—have been reported to AHPRA, many of them vexatious reports from hospital staff.

Hospital staff have been known to use their power to threaten, coerce, bully and report privately practising midwives and women for being "difficult". If women and midwives feel they can't stand up for themselves, it

compounds their trauma. True collaboration is not just about the relationship between the woman and the care provider. It requires the care providers to trust each other and put their egos aside to put the birthing woman's needs first, and that includes not just her physical needs but her emotional needs. Given the selflessness and courage needed for a woman to transfer to hospital from a planned homebirth, putting her own emotional needs aside to put the wellbeing of her baby first, particularly if she has experienced previous trauma in hospital, we consider that a homebirth transfer is a successful homebirth. We recently asked our social media followers to share their experiences of homebirth transfer, and the majority identify them as traumatic. I will read just a few of the responses that we received:

- I was met with judgement and criticism from some of the special care nurses. I received comments such as "it's always the home birthers" and "there is always a problem with a Homebirth."
- The paediatrician went down to the special care nursery with my partner, announced to the other staff that we had a homebirth transfer and said "the mum didn't receive any prenatal care so let's treat the baby as if mum had gestational diabetes". My wife argued that I HAD received prenatal care including testing negative for GD, and the paediatrician turned to her and said "Sorry, who are you in all of this?" She refused to refer to my wife as our baby's mother.
- The OB started talking to her colleagues (while I was still getting the anaesthetic in), saying that I was attempting to freebirth and when I "couldn't figure out what I was doing" I called a random midwife I knew to come over and assist me.
- The OB told me that if I attempted another homebirth and presented to that hospital, I would be turned away and refused treatment. This OB told me that my choices were reckless and dangerous.

We've compiled a full list of the experiences women shared with us about their homebirth transfers, and we will make it available to the Committee for review. Women are being robbed of a beautiful and empowering birth experience that could still occur in a hospital environmental after transfer if they were just treated with humanity, because birth is not just a physiological event; it is a rite of passage that deserves to be treated with the utmost respect.

As mentioned in our submission, the solutions we propose to reducing birth trauma are the same that midwives and women have told us. More availability: more publicly funded homebirth programs and expanding the capacity of existing programs; ease the restrictions for women being able to access these programs and change the legislation regarding collaborative arrangements, in line with Federal Government recommendations. More accessibility: remove the barriers for midwives in private practice such as the non-evidence-based requirement for two midwives to be present at a homebirth, which has all but eliminated privately funded homebirth out of rural and regional areas; remove the need for written collaboration with other medical professionals and let midwives practise autonomously to their full scope; offer funding reform with bundled funding to allow all women to access the care model of their choice, including funding for homebirth, which will ultimately save the Government money.

More education: help provide education for all women on their rights and their birth options. GPs are the gatekeepers to birth choices, but they must provide unbiased, evidence-based information to women, including information on homebirth options and how to access them. Educate health providers—in particular, hospital staff—on informed consent and woman-centred care. There should be mandatory training for hospital and ambulance staff on the best way to facilitate homebirth transfer. More accountability: There must be strong repercussions for health providers who violate women's rights and obstetric violence to be recognised as a criminal offence.

The CHAIR: Thank you so much. I might start with a few questions. First of all, these are quite broad, so I'm happy for anyone to jump in. There has been a lot in the media recently about freebirth. I want to, first of all, hear the difference between a homebirth and a freebirth. Also, is it the case that more women are birthing outside of the system because of the trauma that we're hearing about? Are a lot of people moving into homebirths as a second birth after experiencing trauma in the first birth?

AIMEE SING: I'll let Katelyn talk about the percentages, because we actually have done a survey on this. Briefly, the difference between freebirth and homebirth is that homebirth is birth with a medical care provider in attendance and freebirth is without. Do you want to continue?

KATELYN COMMERFORD: As far as choosing to birth outside of the system, as a result of prior trauma, we did recently survey our communities and our members and found that, yes—which was as suspected. Being a grassroots organisation, we hear a lot directly from our communities as it is, but now we do have specific numbers. I don't actually have the specifics in front of me, but it is around 70 to 80 per cent. That was both from midwives, as to their caseload reporting the prior trauma, and also for first-time mothers. It was actually higher rates of first-time mothers being motivated by a desire to avoid trauma. There was a higher proportion of them, compared to the disclosing of trauma for second-time and subsequent mothers.

The CHAIR: Can I ask you on notice to give us that exact data?

KRISTYN BEGNELL: Absolutely, yes.

The CHAIR: That would be fantastic.

KATELYN COMMERFORD: We can provide those surveys on notice, for sure.

The CHAIR: Great, thank you. Was there anything else in those surveys—any data points—that you felt were particularly pertinent for homebirth?

KATELYN COMMERFORD: Certainly, as far as the access, we asked women whether they ended up with issues accessing homebirth or whether they faced any issues accessing this kind of model of care. Many of them reported that there was no publicly funded homebirth models around them or that they weren't applicable to those models because there are certain risk categories that have them what has been referred to as "risked out" of those models. For example, VBAC women—women planning a vaginal birth after a caesarean—make up, according to the numbers we surveyed from our midwives, nearly 20 per cent of their case loads, on average. Those women wouldn't be applicable to, either, publicly funded homebirth. They'd be risked out of that model. There are access issues from just being able to literally find the care. There's also access issues financially. Financial is the biggest factor without a doubt. As Aimee said in our statement, families are thousands of dollars out of pocket because of this lack of intrapartum Medicare rebates for a private homebirth.

The CHAIR: You have predicted my next question there. I know both organisations have argued for an expansion of publicly funded homebirth programs in New South Wales. Is there somewhere else in Australia—and maybe I'll ask Homebirth Australia—is there a State that's doing this better than we are in New South Wales?

KRISTYN BEGNELL: I'm not sure of the proportion of homebirth publicly funded programs in the other States compared to New South Wales, but six out of 18 is pretty high. I think Victoria probably has the next highest. Some of our homebirth programs are relatively new. I think the issues we hear from our members all across the country is that they all have similar problems: There are not enough spots, women being risked out, and not enough people know about them before. Like, they're probably harder to get into than an MGP model.

KATELYN COMMERFORD: They have to usually be on the MGP model before they can be approved to be on the homebirth model. The MGP access in itself, as you've heard throughout the hearings, is hard enough. Then to also be able to find a spot in the publicly funded homebirth programs is even more difficult.

AIMEE SING: There is some research that actually backs up that with these publicly funded homebirth models a lot of women are scared of being risked out of them, and many women are risked out of them, sometimes as late as 42 weeks into their pregnancy.

The CHAIR: It's a dramatic change from what their actual birthing plan was going to be.

KATELYN COMMERFORD: It's often unconfirmed. In some of the programs, women have recorded that it's tentative until they make it to a certain point where they've gone through the required screenings and everything has been ticked off, essentially, and approved. It's not actually that it's a decision that they've made that is then supported with the system. Jumping through hoops is how it has often been described.

The CHAIR: Kristen—thank you.

KRISTYN BEGNELL: I just want to add something to the end of that, sorry.

The CHAIR: Yes, please.

KRISTYN BEGNELL: The problem with that is then that these women are left without a care provider very late in their pregnancy. It's way too late to hire a privately practising midwife, even if they could afford one. So some of those women, especially if they've chosen to homebirth because of previous trauma, might then freebirth, because that's the only option they feel they have left. So, yes, it's—

KATELYN COMMERFORD: It's probably a case of also—Kristyn, sorry to cut you off—

KRISTYN BEGNELL: That's okay.

KATELYN COMMERFORD: But we heard from a woman who went into labour at home who was under a publicly funded model, and her waters broke at home, with meconium, which then is a category that's excluded from the publicly funded homebirth option. She spoke to her midwife. Her midwife said, "I can't come to you. You need to come to the hospital now you're in this category." She was already in well established labour and unable to get to the hospital. She ended up birthing at home, unassisted—not what she wanted at all—but because she was in a position where she was sort of abandoned by that actual program, her baby ended up with meconium aspiration syndrome. She has expressed regret about the fact that she wonders whether that would have happened, had a midwife been able to attend to her in labour.

The CHAIR: Yes. I guess my other question is: How do we deal with this then? Obviously, there will be situations where it sounds like women are being risked out, first of all, too late in the process in some cases and maybe they're being risked out where maybe they didn't need to be risked out. But where does that line sit? Is there a position where there are certain situations where they should be risked out, or are you advocating for something different here?

AIMEE SING: I think what we need to be doing for women and midwives alike is have a level of protection that the midwife can suggest, recommend transfer to hospital and, if that woman is unable in that moment, or in fact if she declines that transfer, that there are protective measures for that midwife to maintain attendance with that woman throughout that birth—like an actual obligation to stay with the woman. Also just being very clear about these sorts of hurdles to publicly funded homebirth models early on, talking about, "If your waters break and there's meconium, it will be recommended you go to hospital. If you get to 42 weeks, you will have to birth in the hospital." Being very clear with women up-front would be fantastic.

KRISTYN BEGNELL: I think part of the problem could be, too, that a lot of midwives working in the hospital system just don't have the experience with physiological birth. So a privately practising midwife who's had at least 5,000 hours in the hospital system before she can work in private practice is well equipped to deal with a situation like that at home, whereas the hospital—it's just about the level of risk that the hospital is willing to take on. I know that when publicly funded programs are first in development, there's usually a lot of opposition from the obstetric teams at the hospital. It's just overcoming and trusting in midwives and their scope, because midwives are well equipped and trained to deal with situations like that. But, again, in a hospital they just don't have the exposure to an undisturbed physiological birth, so it might be a confidence issue for them as well.

The CHAIR: Ms Maddock, you talked a bit in your opening statement as well about the poor treatment that women have received after they've left homebirth and gone into the hospital system. What sort of recommendations, or what should we be looking at as a Committee, to stop that from happening? Is it education and training around hospital staff, or is there something else that we need to be doing so that a woman that's going from a homebirth into a hospital system will feel supported?

VIRGINIA MADDOCK: I think having supported pathways where the care providers are able to talk to each other as colleagues. There is quite a hierarchy where it's very kind of top-down authoritarian—you know, the obstetrician at the top, where the midwives are seen as the handmaidens and homebirth midwives are seen as even lower, like they're taking unnecessary risks or whatever. But the fact is that homebirth midwives actually have a very high quality of education behind them. They need to have certain training that hospital midwives don't need to have, because in the event of anything being stepped up in urgency, they just hand that over to the obstetrician, whereas at home the midwife actually has to have certain extra qualifications to be able to handle things.

The difference also in the hospital is that midwives are often coming and going. They're not sitting with the woman throughout the whole labour, being able to actually really see the fine little nuances of the gradual escalation of what can happen when babies start to not be able to cope with the labour as well. Because in a homebirth situation the midwife is there throughout most of the labour and is able to really have a look at the little changes, they would normally transfer to hospital in plenty of time before it gets to that real urgent emergency. They need to be given the respect of being autonomous care providers in their own right and be able to really practise to their full scope of practice as a midwife, defined by the international midwives standards.

AIMEE SING: Can I add to that as well? In terms of transfer pathways, there is one hospital in New South Wales that provides admitting rights to privately practising midwives. That enables true collaboration in the midwife transferring the woman in, and the woman has often met with the obstetrician that will be overseeing her care. It creates a completely different framework for a transfer pathway. Women often experience much less trauma from being supported by their own midwife, and their midwife can continue to provide medical care for them, whereas in other transfer situations, they can't.

The CHAIR: I have got one more question for Homebirth NSW specifically. We had some witnesses argue that continuity of midwifery care is not possible within the public health system due to expenses and it being too costly. However, I note that you suggest in your submission that it may actually save the health system money. Can you give us a bit more detail on that and how you have crunched the numbers there?

KATELYN COMMERFORD: That's actually a study—I don't know if I have it off the top of my head.

AIMEE SING: There are multiple.

KATELYN COMMERFORD: There are a few. Scarf et al. is the one that I was referring to, from 2021. Gratefully, Aimee has put the notes down here for me. From Scarf et al. 2021, the average cost per place of birth was calculated to be \$4,748 for homebirth, \$4,979 for birth in a birth centre and \$5,463 for planned hospital births.

When the cost of antenatal care is included, it increases by \$2,104, resulting in total costs of hundreds, thousands and millions of dollars, essentially. In Tracy et al. 2013, the total cost per woman was \$566.74 less for midwifery-led continuity of care than standard care. There has been research done on this topic. That's what we're referring to. If you would like us to take that on notice and provide those studies—

The CHAIR: That would be fantastic.

Dr AMANDA COHN: I wanted to pick up on the thread about transfers, because this is a really important bit of detail for us to get right. In the Homebirth NSW submission, you talked about homebirth being safe only when hospital transfer remains possible and straightforward. You've also criticised mandated collaboration. From a government perspective, it's easy to understand why they've mandated collaboration. There is obviously an intent there that privately practising midwives have an automatic referral pathway, whether that's to a particular maternity service or a particular obstetrician. You've asked for genuine, rather than mandated, collaboration. I was hoping to unpick that a bit more. What specifically do you mean, understanding the intent of government in mandating collaboration as beneficial?

KATELYN COMMERFORD: It's a good question. Essentially, the mandated collaboration is more in respect to the fact that a GP referral is required. It's not necessarily to do with the collaborative arrangements between midwives and hospitals but actually the GP ends up being the gap-filler, I suppose, which doesn't really assist in the event of a transfer because the GP is removed from that scenario anyway. Genuine transfer pathways that are created with genuine collaboration, like we see in Westmead Hospital, which is the one that has admitting rights—that's an excellent example of how things can work really well, where there's a relationship with the obstetrician. It's more about relationships and respect for the work that these private midwives are doing with women.

We hear from midwives all the time that they transfer in with women and they're not listened to when they're handing over the information about here's clinically what's happening, here's why we've transferred and here's what was going on before. They're told that the hospital needs to make its own assessment, delays in care occur and then women end up with more interventions than they needed had they taken that midwife's information on face value and said, "You're telling me that this is what's going on. We'll treat it as that and we'll make our assessments as we go while we're doing that." But there are often delays to that care occurring as a result of this distrust of that midwife's practice.

Dr AMANDA COHN: To pick up on that, I understand that some of the publicly funded homebirth models would be staffed by midwives who are also employees of the same health service. A number of privately practising midwives would've trained in that health service to do their compulsory number of hospital hours. Does it make a difference when the privately practising midwife or the homebirth midwife is known to the maternity service?

KATELYN COMMERFORD: It does. I'm not so sure about the facts where midwives are trained and that kind of thing. Speaking anecdotally, as a woman who transferred during my planned homebirth, it was something I was terrified of because I'd heard stories of the mistreatment, the abuse, the coercion and everything else. The hospital staff, it was clear, knew and trusted my midwife when I arrived. There was no official pathway in there, but there was a real respect for who she was in the community, the service that she was bringing, the competence level of her care and how that affected how I was treated as a result—the way that we were easily put through into the birth unit and things were assessed. Even postnatally, I had midwives in the ward, having read my notes, saying, "Yes, you're such and such's client. We know who she is and we respect that."

From a perspective of when the health services are willing to engage with the midwives and create this pathway—I know I've heard in the past from some of our privately practising midwives that a lot of the reporting seems to come from a place of that hospital, when they don't know the midwives well and they don't have a relationship, they don't feel like they have anywhere else to go if they do have concerns about the way that woman's care was given or not given. But when they do actually communicate with the midwives, organise meetings and all get together and actually build a relationship that develops there, those pathways are much more seamless. It makes sense; they trust each other.

AIMEE SING: What Katelyn is referring to is what we termed in our opening statement as "vexatious reporting". A lot of midwives end up vexatiously reported—estimates of up to 50 per cent. These are reports that are only made from the perspective of a disagreement, possibly, rather than true collaboration and talking to the midwife about that situation. I would also suggest, and I don't know if it's actually possible, that a privately practising midwife would be the best to talk about these experiences.

KATELYN COMMERFORD: Our organisation doesn't have privately practising midwives on the committee anymore because they are so busy.

Dr AMANDA COHN: If it's any reassurance, we have had a couple.

KATELYN COMMERFORD: That's great.

Dr AMANDA COHN: We have got an extended session today to talk about homebirths. I have another question on a completely different topic. In the Homebirth Australia submission, you talked about the need for better access to breastfeeding support and lactation consultants. I was hoping you could expand on that a bit more.

KRISTYN BEGNELL: I wrote that submission a long time ago, so let me just bring it up to remind me what I said.

VIRGINIA MADDOCK: While you're looking that up, can I just make a comment? When you're asking about the collaborative arrangements, prior to 2010, when the eligible midwife registration standard came in, midwives were already doing that seamlessly anyway and documenting that. They get performance reviews every—I don't know how long it is—couple of years, I think. It was the Australian Medical Association, the rural doctors group, that ensured that the requirement became a signed collaborative arrangement for the medical practitioner. That was despite opposition from all midwives and consumers who were at the table. But that made it through, which demonstrates the power of medicine when it comes to these negotiations. It would be great if we could reverse that requirement, because all of the key stakeholders disagreed with it at the time. It's a shame that got through because of doctors pushing for it.

KRISTYN BEGNELL: That came up when we did our initial submission and we asked our members and followers to give us their feedback. Something that I experienced in my homebirth transfer is the conflicting advice that you get from midwives in the postnatal ward, and breastfeeding is one of the biggest things. So in a single day, I could be told five different things by five different midwives. That's a common thing that we hear from women birthing in hospital all the time. Privately practising midwives, some of them are international board certified lactation consultants, and that's the gold standard in breastfeeding support. That note in our submission is that 57 per cent of our respondents identified as experiencing breastfeeding trauma, which is separate to their birth experience, but often women who haven't had the birth that they wanted to have—I can speak for myself personally. Breastfeeding was the next thing that I really, for want of a better word, latched onto because it was the only thing I had left in my control, and it is something that's really important. If it's important to a woman, they need to be getting the right support.

AIMEE SING: I can attest to that as well. I had a homebirth transfer where I didn't have trauma from my birth process but absolutely did from the breastfeeding "support" that was provided me in that hospital setting.

The Hon. SUSAN CARTER: Thank you all very much for being here. Homebirth Australia, when talking about the referrals, talked about the issue of GPs and insurance. Could you tell me why it is an insurance issue for a GP to write a referral?

AIMEE SING: Good question. We actually have a report on this. It was done a few years ago, and we can take that on notice as well and send it through to you if that would be beneficial. In surveying GPs and learning to understand what was going on—we surveyed women and we also surveyed GPs to try to understand what was happening in terms of the referral refusal situation because, progressively, GPs are refusing to refer. More and more we are seeing this in our community. The GP that provided me a referral contacted me recently saying, "I can no longer do it. My insurer has contacted me and told me I am no longer allowed to." We aren't allowed to speak to the GP insurers. If we try to contact them they say, "You aren't one of our clients."

The same goes if a privately practising midwife tries to contact them and speak about it. So we are kind of being barred at that point. But one of the key reasons that GPs provide, both to women and us, as to why they can't refer is because they aren't insured if something goes wrong in a homebirth setting. There is this idea that they would be responsible from a medico-legal perspective, which I know Bashi Kumar-Hazard talked about in the first day of hearings.

KRISTYN BEGNELL: I just wanted to add, a few years ago Homebirth Australia organised a panel discussion on this very topic because it's such an issue. Probably one of the most commonly asked questions in homebirth support groups from women is, "How do I find a GP to give me a referral?", because without that referral they can't get the Medicare rebate and then it becomes even more unaffordable. And GPs are not referring for the birth period. They are only referring for the antenatal and postnatal period, so there is a lot of confusion in there around that. I would be happy to send a copy of the recording for that panel discussion if you think it would be helpful.

The Hon. SUSAN CARTER: Thank you. Do midwives have issues getting insurance?

KATELYN COMMERFORD: Midwives currently have public indemnity insurance for their antenatal and postnatal care. They have no insurance for intrapartum care, and this is an ongoing issue that has been brought up. The Government gave them a—

AIMEE SING: Temporary exemption.

KATELYN COMMERFORD: —temporary exemption to be able to practice without that insurance. That just keeps getting renewed. The actual issue at hand doesn't seem to be getting resolved properly. Every time they go to a birth, that's their livelihood on the line.

The Hon. SUSAN CARTER: Is that actually because of the experience of risk if you've got midwives involved in the birth?

KATELYN COMMERFORD: There was an insurer who was giving them this level of insurance, and then they decided that they were no longer prepared to, which is confusing because I don't believe the risk has changed at all in that time, and yet a decision was made no longer to provide it.

The Hon. SUSAN CARTER: What is the situation of a woman if there is a problem in the birth and she sues the midwife? She either takes the midwife's house or there is no recovery?

KATELYN COMMERFORD: Essentially.

AIMEE SING: Exactly.

KATELYN COMMERFORD: In speaking with midwives, I think that the only reason that they are prepared to do the work that they do without insurance is because they build a trusting relationship with their clientele and their women, but at the end of the day they don't have that protection.

The Hon. SUSAN CARTER: You have talked about the cost of private midwifery. Is that covered under private health insurance?

AIMEE SING: No.

KATELYN COMMERFORD: There are a couple of insurers who provide very small amounts but, on the whole, no, not in the way that private obstetrics is covered.

The Hon. SUSAN CARTER: When you talk about the concept of being risked out, is that because as the pregnancy proceeds gestational diabetes or other risk factors might develop, and at that point there is a medical assessment made that this model of care is no longer appropriate and a different model of care is required? Is that what we are talking about?

KATELYN COMMERFORD: Yes, precisely.

AIMEE SING: But that's in a publicly funded homebirth model typically. What happens if the woman has a privately practising midwife is that midwife will continue to give them care with collaboration with an obstetrician or whichever care provider needs to be collaborated with.

KATELYN COMMERFORD: And in discussion with the woman.

AIMEE SING: Yes.

KATELYN COMMERFORD: The woman will always be given her full range of options. If she chooses to transfer her care to hospital—under hospital environment—in that case, that's always an option available to her too.

The Hon. SUSAN CARTER: Who funds the collaborating health practitioner?

KATELYN COMMERFORD: The public health system, generally. In the case of the collaborative agreement at Westmead Hospital, that's a private model, and the women pay for that additionally when they—

The Hon. SUSAN CARTER: Sorry, I am missing something, because I thought you said that in a public model it would be transferred to hospital but in a private model there would be another practitioner who would come in and co-treat.

AIMEE SING: In a publicly funded homebirth model, women are risked out and they're basically told, "Go to hospital." So that's the end of the care from that particular midwife in some instances. I'm not entirely sure.

The Hon. SUSAN CARTER: So it's an allocation of resources issue.

AIMEE SING: Yes, that's the publicly funded. In a privately practising model of care, the woman can maintain that privately practising midwife. If they have a collaborative agreement with a specific obstetrician, that woman can then be transferred into collaborative care between the midwife and the obstetrician.

The Hon. SUSAN CARTER: And if there is no collaborative agreement?

AIMEE SING: If there is no collaborative agreement, they would potentially transfer to their local hospital and then, if the woman decides to birth in the hospital, the midwife provides support but in a doula capacity, essentially. So they aren't able to be the medical care provider for that woman.

The Hon. SUSAN CARTER: If you are thinking about the insurance, therefore—arguably legally—the midwife isn't able to manage that birth because the hospital would have somebody uninsured managing that birth.

KATELYN COMMERFORD: Yes, technically the midwife has to hand over the duty of care to that midwife, to that hospital.

The Hon. SUSAN CARTER: That makes sense. Thank you.

The CHAIR: Thank you for coming today and providing your evidence. It has been really helpful. The Committee will be in contact with you about the questions taken on notice, and if the Committee has any further questions, they will be sent through as well.

(The witnesses withdrew.)

(Short adjournment)

Ms EMILY CASKA, CEO, Down Syndrome NSW, sworn and examined

Ms MELISSA COTTERILL, Prenatal and New Baby Manager, Congratulations Initiative, Down Syndrome NSW, sworn and examined

Ms KYLIE PUSSELL, CEO and Co-founder, Miracle Babies Foundation, sworn and examined

The CHAIR: Thank you and welcome back to our inquiry into birth trauma in New South Wales. I now welcome our next witnesses. Thank you for coming today and giving your time to give evidence. Is there an opening statement from Down Syndrome NSW?

EMILY CASKA: Yes. Firstly, thank you for this really important inquiry and particularly to the Hon. Susan Carter for giving us the nudge to be here today, because it is such an important topic for us, as you've probably seen in our submission. We warmly welcome it. Down Syndrome NSW was started in the '80s by families who were told, "Leave your child at the hospital. We'll take care of it. We'll take it to an institution. Tell your friends and loved ones that you had a miscarriage, and we'll work it out." That was the prevailing attitude at the time. It's really hard to hear. When you think about it, it wasn't that long ago. It's interesting to come to an inquiry like this where we've maybe come full circle, but we haven't, because we're having the same conversations but in a different context. It's really important for us.

I've been involved with the organisation for 20 years. I started working here when I was at university and have done other things in the sector. I've come back to Down Syndrome NSW specifically in the last four years. This is the biggest topic on our families' minds. Personally, as a mum, I don't have a loved one with Down syndrome directly. My sister has severe intellectual disability. But what has blown me away is the treatment that our families and new bubs are having in the health space in New South Wales in this day and age, which our submission speaks to. I'm happy to answer all questions as you wish. You may have seen, we had the real privilege of sharing some of those stories on the ABC last Friday, which was amazing and an absolute credit to our families. They're the families who are brave enough to talk about it. This inquiry is so pertinent because a lot of families, even with children who are in their twenties, thirties and forties, aren't ready to talk about their prenatal and new baby experience. To me, that's why this really matters.

Then we also did some LinkedIn posts, and I've been overwhelmed. Writing the submission and being in this sector, I knew it was an issue. The last week has shown me it's an even bigger issue than what I thought. Before we even speak about our evidence, to be clear, what has blown me away is that this isn't an issue that affects maybe 10 per cent or 15 per cent of our families. That's still a big issue. I can honestly say that there is a handful of families who say they had a great prenatal experience—in the hundreds. I would say, at a guess, that 95 per cent or 98 per cent of our members say their prenatal, new baby experience was far from optimal and there is trauma, grief and a lot of residual issues that are coming up from that. The solution to that is actually really simple.

Coming from that base, as we've said in our submission, we know that in Australia, depending on what incomplete dataset you look at, the termination rate of babies with Down syndrome is between 90 per cent and 97 per cent. We absolutely respect the choice of families, but we know from those same families that, whichever choice they've made, they're being given outdated information. They are being told that the life expectancy is around 10. It's 60-plus. They're being very much pressured to terminate from the voices of health professionals. I'm very aware that I'm using that as a blanket term but, like I said, when I've got at least 95 per cent of parents telling me this is their experience—and I speak to a lot of parents and I've been involved for 20 years. There are great health professionals out there; don't get me wrong. But families are being told that this is the natural next step. And it's not just once. It's at every single appointment, even where those families have said that their decision is clear and have said, "Please write it down on my notes."

There are always a lot of discussions about limitations, complexities, what this child won't do, can't do and will never do, and the issues it's going to cause for the family. There are very limited, if any, discussions about what they can do, the possibilities and the joy that our loved ones absolutely bring to our lives. As we've said in the submission, this is a direct breach of the UNCRPD. I think that's fairly obvious, but when I say that, it's the whole process. It even goes back to why you are having the prenatal testing and what is being picked up. We know that it picks up around 800 conditions.

We also know that, anecdotally, out on the street, it's known as the Down syndrome test. We know that through getting that prenatal diagnosis, there are some families who still do get a postnatal diagnosis right through to families who you may have heard in the ABC article, who are told, when they're taking their three-day-old baby home from a hospital, within the last two years—so these aren't old examples—"Oh, you're still taking her home?" That's what our families are going through today. The support, particularly this last week from our families, is we

need to put this out there. It's hard to talk about. It's hard to hear, but we're here to fix it, with you all in a partnership approach.

Families we speak to, who have amazing loved ones with Down syndrome in their forties and fifties, can very acutely recall how their diagnosis was delivered and the impact it had on them. We had a new babies day on Saturday where we had around 60 people—our biggest yet. Families only a few months old had the same sorts of experiences. For me, coming back into this in the last five years, I think, "Wow, we haven't really changed much, have we?" This is really important to us. When you also zoom out, we have the DRC. We're talking about inclusive education, inclusive employment and better health care and housing.

The NDIS talks about the importance of early intervention. We have a whole cohort—a whole population—who en masse are being told, "There's no place for you here", before they're even born. Coming from that and the trauma that ensues from that—I don't know if it's connected—we are seeing families not accessing early intervention as early as they should. There are a lot of other impacts that aren't seeing our guys, when they are here and thankfully so, taking the trajectories that they should. As much as I support all those bigger conversations, we've got to bring it right back to start of life.

To speak to the terms of reference of this, the trauma is significant. A lot of it does centre around informed choice and informed consent. The trauma is lifelong and it's not just for the parents. It can also be for the siblings, because they hear the conversations and they're involved as well. It's not just for the mums; it's for the dads. They're often not getting a light shone on their experience. As we've said very clearly in our submission, we've had to take things a bit into our own hands. We've instigated our own project, which Melissa runs and can speak to. Every parent in New South Wales deserves a congratulations, not a sorry. For the vast majority of families I hear of who have the diagnosis of Down syndrome, or a chance of it, sorry is the first word. It's a very negative conversation. I firmly believe we can get this right for new bubs and families with a bub of Down syndrome. We can get it right for everyone in our health system.

MELISSA COTTERILL: Down Syndrome NSW Congratulations Initiative was developed in its current format in August 2022. As Emily echoed, it started up over 40 years ago basically in the same vein, using generously donated funds to pilot this project. Our aim is to ensure the very best start for all babies with Down syndrome and their families. Demand is outweighing our capacity to deliver fully at the Congratulations Initiative. The initiative has had a significant impact in such a short space of time. The project covers three main streams. The first is to nurture and support families in the prenatal and new baby stage. The second is to upskill medical professionals with a prenatal and postnatal diagnosis. The third stream is robust data—a collection of data of babies born in Australia. At the moment there's no dataset of that information. I come into this today with a personal experience. I'm a mum of a child who has Down syndrome. She is almost 18. My experience was a really good one, but that's just a drop in the ocean to what the parents who we speak to, who have a prenatal diagnosis and postnatal diagnosis, experience. Our Congratulations Initiative is working. We're seeing results, and it's having a huge positive effect on families.

KYLIE PUSSELL: I emailed through earlier my personal story submission. Thank you for accepting that. I wanted to start off by saying thank you for having us. It's definitely a long conversation that has needed to happen, so thank you for including us. We support premature and sick babies and their families, and come from a similar perspective. Miracle Babies Foundation thanks the Select Committee for the opportunity to present the impact for mothers and babies. We know separation often culminates in anguish, desolation and the trauma experienced by a mother after discharge and when her baby stays in hospital. Going home without her baby is the most difficult thing a new mother may experience. This event is recalled as trauma for women who experience it. We acknowledge the support the New South Wales Government has given the Miracle Babies Foundation to deliver peer-to-peer support for families who have a preterm or unwell baby, during and after their hospital stay. Sadly, though, the demand for our services is far greater than Miracle Babies can provide.

Parent and baby separation is one of the most significant causes of trauma amongst the families we support. We support the principle of NSW Health's blueprint for maternity services that women and babies should stay together during the postnatal inpatient stay. This principle should be more explicit so that change is mandated, it's implemented, funded if required and the success is measured and reported on. The New South Wales Government's parental leave scheme is socially responsible because the qualifying period of employment is 40 weeks but parents with a baby born early may miss out. We seek permission to give the Committee some reports and further evidence to our submission that was emailed through again today and a copy has been given to you all.

The positive outcomes from zero separation include increased rates of breastfeeding, better childhood development and physical outcomes, maternal distress is lowered, and neonatal mortality is reduced in some situations as well. For women whose babies aren't critically ill, they also suffer from separation. Well babies are

taken from their mother after a caesarean. Needless separation occurs when a baby is admitted to a neonatal unit for a non-life-threatening problem. The mother's discharge may happen even though their baby may be discharged the following day and her milk still hasn't come in yet. The immediate impact is on successfully establishing breastfeeding for these parents and babies but longer term the trauma from not being with her baby. And these traumas have a greater impact on isolated, disadvantaged, rural and Indigenous women, as we know.

We recommend all maternity services should ensure that well babies stay with their mother, especially after a caesarean section. Babies with straightforward conditions should receive couplet care—that is, cared for with the mother and baby together. Home-in-the-hospital accommodation should be available for all families who wish to stay with their baby. Maternity units should implement models of care that ensure the family, especially the primary carer, is able to provide the care needed for the child throughout their admission, and neonatal units should link families into peer-to-peer support services with the lived experiences of us here today.

The Hon. SUSAN CARTER: Thank you, ladies, for all being here today. I think it was you, Ms Caska, talking about the prenatal test which can diagnose up to 800 conditions. Are you aware whether families who are having a child with a different diagnosis other than Down are also subjected to the same pressures that you have described your families being subjected to?

EMILY CASKA: Those that we hear from, yes, because we do have some families where they do have other children with other diagnoses. So, yes, I think it is happening in that area as well, but I can't speak to the specifics of it.

The Hon. SUSAN CARTER: Would that then likely discourage mothers from having that testing undertaken at all?

EMILY CASKA: Absolutely. There are a couple of reasons why. There are risks associated with particularly the second stage of testing, but it's probably something Melissa can refer to because when she said in her opening statement that she had a good experience, which truly is a drop in the ocean, part of that reasoning was around her choice of testing, which I know she'd like to touch on.

MELISSA COTTERILL: My husband and I have four children and we decided not to have any prenatal testing. That decision, a lot of it was due from experiences that I encountered with people in my social circle where they were particularly testing for Down syndrome, and back in those days when I was in my early twenties it was like a three-week wait to find out and it was just all about Down syndrome and just how negative and how traumatising—the information that they received—it would be to have a diagnosis of that. And then also I actually worked with someone who had the amniocentesis testing, which is the diagnostic testing, and unfortunately she lost her baby as part of the risk of that, so that was traumatising.

So I didn't actually have any prenatal testing. I remember the obstetrician very clearly saying, "Do you want to have any testing?" And I just said, "No, we're not interested." So my experience postnatally was a very positive one. But like Emily said and what we're experiencing talking to the parents in prenatal stage and the postnatal stage—we speak to them in both those stages—it's very different, and every single visit they go to to see their doctor they've been asked relentlessly do they want termination when it's very clear that they're going ahead with the pregnancy.

The Hon. SUSAN CARTER: So after the first diagnosis has been made and after there's the first discussion, "There's this diagnosis, what do you want to do?" and the parents or the mother indicates that she wants to continue with the pregnancy, at every check-up she is being asked again and again and again, "Do you want to keep this baby?"

MELISSA COTTERILL: Yes.

EMILY CASKA: Yes, correct. I'll probably even go back in part of your question. A lot of them are being asked "What do you want to do?" Some of them are being more directed that, "This is what you do and this is what the standard practice is and something you should strongly consider", and it's almost met with quite surprise if a decision is made not to go down the termination path. So that's the start of that process and then, yes, at every appointment it is asked again. We've obviously spoken to some health professionals about, "Is this part of your duty of care?"

And we've also had some families—Liz being one of them—who featured on the ABC who had specifically said to her medical professionals, "Can you write this on my form? I don't want to talk about this at every step", and that was not a right afforded to her, and they're conversations that we've also been trying to have with NSW Health of, "You've got their date of birth. You've got their name. You know they've got the diagnosis. Can you not note this down that the decision has been made, that it's not happening in reality?" Again, this is the vast majority of cases—every appointment—right up to very late term. This isn't a first 12 weeks, 18, 20 weeks

conversation. They're still happening very late term through to, like I said, having a three-day-old baby in the hospital born almost still having those same conversations or surprise.

The Hon. SUSAN CARTER: We've talked a lot in this inquiry about informed consent and making sure women are informed, but it sounds like a number of the conversations that your families are experiencing are health practitioner led rather than women led. Is that a fair characterisation?

EMILY CASKA: Yes, very much. What our families tell us—obviously in those moments, it's difficult for any parent, but I think you think the health professional is the expert in this area and that they will give you that balanced scorecard. And I think us as the peak body and what families are telling us is that it's a very one-sided discussion, as I said. And not just one sided; the stats are quite frankly out of date. But they're not being connected into organisations like us, to other parents who have walked that path, again, from our point of view not to necessarily change the choice at the end but, like you say, to give that informed choice, the actual information about Down syndrome, hearing stories of what people with Down syndrome have done with their lives and what the possibilities are. That's absolutely not happening. It has probably only happened in the recent years because we've pushed through our project very proactively to get in. I have to say, the medical professionals on the ground are welcoming it. It's like they can't get more information from us if they tried. But, yes, the informed choice is absolutely not being afforded to our families.

The Hon. SUSAN CARTER: You raised an issue that I don't think we've heard about before, which is sibling trauma. I'm just really interested in that because we've looked at it from mothers' trauma, fathers being caught up in it, but brothers and sisters also being affected by these discussions.

EMILY CASKA: Absolutely. Siblings are a part of it. Particularly where they've got young siblings, they're being taken along to a lot of the appointments because of caregiving responsibilities. Absolutely, the siblings are privy to and hearing all of this. They're knowing that this baby coming, there's some negative connotation about it—again, if that baby does make it given the statistics. But also we find it's the first question that families ask and it seems to be some of that messaging that they're getting from the health professionals that this is a bad thing and you're doing a bad thing to your family by taking this path. We find that a lot of the questions are, "What's the impact on the brother and sister? I'm doing the wrong thing by them." So there is absolutely sibling trauma as part of this.

The Hon. SUSAN CARTER: Ms Cotterill, from your lived experience, what has the impact on your daughter's siblings been of having her as a member of your family?

MELISSA COTTERILL: Amazing. Absolutely amazing. She's got three sisters and they're just fully involved in her life and always have been. The early intervention, we started when Alyssa was four weeks old—well the older two; I've got a younger one younger than Alyssa. But they were fully involved in her development and just absolutely love her. It has really benefited them having a sister in their lives, definitely.

Dr AMANDA COHN: Thanks so much for all being here today. It's a really important perspective that we haven't heard yet. My question is for Ms Pussell. We've had a lot of lived-experience witnesses tell us about the experience of separation itself being more traumatic than whatever medical incident had happened to either the mum or the baby, so I'm really interested in the evidence that you've provided us about family-integrated care models. It's really interesting to have some evidence-based solutions for the Committee to consider. My question is if you're aware of any examples of that sort of unit in Australia and how that's going.

KYLIE PUSSELL: Not so much in Australia. It's definitely a movement that's happening globally a lot. A lot of countries are trialling mother and baby or couplet care units. It's definitely something that's recommended by the World Health Organization as well. As we move into new builds in NSW Health, I've noticed in some of their units there is sometimes capacity for a stretcher bed or something, but it's certainly not a welcoming environment where we can care for mum in her postnatal period next to her baby. Exactly as you said, the main thing we hear from parents, especially in those first few weeks, is the trauma of being separated from their baby. Most of the time they're not informed or prepared before they are sent home that their baby will remain in hospital for days or weeks or months, so that comes as a real shock.

The access of being in the same hospital and being able to go to the nursery whenever you can to sit with your baby or care for your baby is the time that we should be having those conversations to prepare these mums. They're getting up in the morning and it's, "You're going home today. See you later", and they're like, "Well, what about my baby?" It's really quite shocking for them, in an already emotional and stressful time. We can prepare better for that. But yes, definitely it's a movement globally that we're seeing. There are some really good outputs across the world with it.

Dr AMANDA COHN: Short of an overhaul of the way NICUs and maternity units are built across the whole State, what are some of the other barriers at a practical level? It is to do with protocols for visiting hours? How can we decrease separation with the physical infrastructure we've already got?

KYLIE PUSSELL: Yes, it's certainly difficult. There is the financial strain as well, obviously, around leave for families as well. It's not just a week at home when you get your new baby; it could be, as I said, months in hospital. Definitely providing more in-hospital facilities for families—if you've got a sibling, it's really hard to visit the unit to see your baby because most units don't allow siblings in at the moment. That limits the time you spend with your baby as well. I think definitely a financial position could be more beneficial for them.

Travel is difficult if they've had a traumatic birth. Their partner, or dad, might be back at work. It's really a time where we want mum to be there as much as we can but we don't give her the best tools to allow her to do that. Definitely around breastfeeding and things like that, she might be sent home and her milk's not in. We know that breastmilk for these babies is vital. The more that we can support mum to do the caregiving duties she needs to do for her baby in that really critical time, I think it's much better—but a lot more home care in the hospital, where mum can be there more often.

The CHAIR: I might just follow up with a couple of questions based on that. In regards to the zero separation after birth, are there any other jurisdictions you're aware of that we can learn from here in New South Wales?

KYLIE PUSSELL: I don't know the exact protocols on visiting for paediatric wards, but I'm aware that a parent is required to be there a lot more time than in the neonatal unit. We keep that quite separate. It's like, "We'll look after the baby and, Mum, you go home", but in a paediatric ward we encourage the parents to be there to care for their children through that time. I think if we can look at how that model works—how we can provide that care for mum or dad to be there—it's maybe something we can look at improving in neonatal units. Also, providing more facilities so some of these babies can be cared for in the maternity ward and we're not taking them away, whether it might be phototherapy for jaundice or some blood sugar tests—things that we can actually maybe upskill people in on the maternity wards so that those babies can stay with their mum, rather than, once again, being separated and going to the nursery.

The Hon. EMMA HURST: You also mentioned two promising models of care in your submission that allow mother and baby to stay together: the family integrated care and the kangaroo mother care. To what extent are those models currently being utilised in hospitals across New South Wales?

KYLIE PUSSELL: Kangaroo care is something that is encouraged all the time but, once again, it's dependent on how often mum or dad or partner can be there. It's very limited by that kind of time frame, I guess, and those facilities to be there.

The CHAIR: You also mentioned in your submission how some families are struggling—if mum is left in the postnatal ward, there's no accommodation near the hospital. I'm wondering if you've done work with families in regional and rural New South Wales and how much they are further impacted by that?

KYLIE PUSSELL: Definitely further impacted. We get calls from hospitals so often at Miracle Babies around parents needing urgent accommodation. Mum can come down but then dad might have to drive down in those stressful situations. Then they actually have to have the finances up-front to be able to link into those schemes and things that might reimburse them, but sometimes the accommodation is not close to the hospital so they're still having to look at transport issues as well. Definitely rural, we're taking them away from their normal community and support networks, so the emotional trauma on them is even more significant.

The CHAIR: You note in your submission that there could be some major cost savings for the Government, as well as positive mental health outcomes for the birth of premature or sick babies, if organisations like your own were able to provide peer-to-peer support to every family facing this situation. Can you let us know what the current barriers are to reaching those families? Is it simply a matter of funding, or are there other barriers that we need to be aware of?

KYLIE PUSSELL: Definitely for us with peer support, it's funding and resources to be able to have someone available in the hospitals more regularly so that those parents can connect. For a lot of families, it's a totally different experience from what you expected. You go into shock. Being able to normalise some of those emotions for where you're at, especially if you haven't known of anyone who's had a premature or sick baby, you are extremely isolated. The more we can provide support people in the hospitals to help normalise these emotions and be there for the families, the greater impact we'll have on trying to help reduce their mental health negative impacts as well.

The CHAIR: I've just got one more question, for Down Syndrome NSW. We've heard a lot at this inquiry about the need for greater funding for postnatal support services. I was wondering if you could let the Committee know what sort of postnatal support services we should also be considering for families with a child with Down syndrome?

EMILY CASKA: I think the biggest feedback we get is it's delivered by and for parents of people with Down syndrome and people with Down syndrome themselves. I think that's really important. I think it's been touched on by everyone, that lived experience, and that's really important. That's what we as the peak body absolutely strive to do. In an ideal world, if we had it, I think our Congratulations Initiative starts that process. But plugging them in at the local level to other families of children with Down syndrome and other disabilities, absolutely, and a really intensive approach that we're trying to do, with our limited funding, in that zero to two age range.

Also, really importantly, it is about engaging the siblings, engaging the dads and nurturing these families through that experience to minimise the trauma that, as I said, almost all of them have absolutely gone through; and connecting them in with early intervention services. We're hearing, as the peak body, that early intervention services across New South Wales and across Australia, probably as an unintended consequence of the NDIS, were seeing bubs, like Melissa's example, really early on. It's a lot more fragmented now and happening a lot later. What used to be a time frame of, generally, getting plugged into early intervention within the first six months, we're seeing it now around the 12- to 18-month mark. That's too long for a lot of our bubs, absolutely.

The CHAIR: What sort of impact is that having for those families if they're not getting that early intervention until 12 to 18 months?

EMILY CASKA: An absolutely huge impact across all the developmental milestones—which you can go through: across physio, speech, OT—but also for the families and the siblings and their strategies at home. Like I said, then we look at those prevailing things around inclusive education, employment, health care—everything is delayed and impacted as a result, without a doubt.

The CHAIR: So it really affects the quality of life of that individual?

EMILY CASKA: It could. That's probably a subjective thing; I couldn't comment. They did a study in the States four years ago where 98 per cent of people with Down syndrome think that their life's great and they're awesome, so I can't comment on their view of their quality of life. But it's definitely impacting their speech development. We know that a lot of the medical conditions associated with the genetic biomarkers of Down syndrome—hypotonia and a lot of the other conditions, such as open heart conditions—could be addressed a lot earlier if they're getting access to that early intervention, absolutely.

The Hon. SARAH MITCHELL: Thank you all for your submissions and for coming today. I wanted to ask a question probably more towards you, Ms Pussell, but I'm happy if the other witnesses want to give any evidence on this issue as well. Thank you for sharing your story. I'm sorry for the loss that you experienced. You talk in the submission about what future pregnancies or further pregnancies were like in terms of stress when you've been through a traumatic experience such as the one that you had.

Are there ways that you think we could make some recommendations as a committee in terms of how we can have better support for that continuity of care, trauma informed, and not having to retell your story again and again? I think it's probably equally applicable to the families that you work with at Down Syndrome NSW as well. What was missing in your experience, if you're happy to share that, but also from your organisation's perspective? Are there things we could do to help those who are having future pregnancies but are obviously dealing with the issues of their past pregnancies as well?

KYLIE PUSSELL: Yes, I guess I was quite lucky; at least I had a wonderful obstetrician, so I had a continuum of care right through for all of my pregnancies. I'm thankful he was the kind of doctor he was, because I then felt comfortable to talk to him about having future children. But I remember every appointment going in and thinking, "Is he going to say, 'Enough'?"—but he never did and he always supported me. I wish everyone had that type of obstetric care. I understand they don't. Even just recently, at some of our groups out at Campbelltown, talking to some parents there, most of them are first-time parents and the mums were just talking very openly, sharing about how they are too scared to have another baby and they can't afford to have another baby. Once again, that emotional and that financial stress is really difficult on families, and then it's that time that they have to stop work or they're longer away from home than what they would've been if they had a healthy, full-term baby that didn't have those extra needs.

So, yes, definitely it is something that is still happening a lot and it is impacting many families with not having any more children. So I think, definitely, improved care and, yes, as we said, not having to repeat the story. That is really traumatic, having to live that over and over every time you have an appointment—"Oh, you've had

this loss" or "This happened last time". I think a lot of the tone, a lot of the conversations from some healthcare professionals can be improved, and not focusing so much on that negativity. So, yes, I think we can definitely work better to find a better, caring way to do that with families.

The Hon. SARAH MITCHELL: Do either of you ladies want to add anything?

EMILY CASKA: I think from our perspective—and, Mel, you can jump in—the feedback from families is, I mean, we heard it just on Saturday at the New Babies Day, "I wish we'd known about you sooner", and that it's not just an automatic thing with health professionals to refer to the peak body that's been around for 45 years because we're there to help. Our recommendations, if you look at them, they're not really asking that much more of the health system. It's more saying, "Hey, we're here, just connect us." We've referenced in there the legislation in the US that mandates that. Health have said to us, when we've raised it, that it is in their policy directives that it should happen, but just simple changes like putting our contact details on the back of the forms and having our medical professionals pack. I would love to be able to say in two years that our medical professionals pack about Down syndrome should be in every hospital and every clinic in New South Wales. That can't be that hard; Australia Post can get them there.

But that's the biggest feedback that the families had—"We just wish we were connected in with you, because we could meet with other families", talk to them about what's possible, get that balanced scorecard, see people with Down syndrome at our amazing events and the talents and the things that they have. The other side of it is it's not all sunshine and roses. There is an adjustment for families when they do get a diagnosis of Down syndrome. Does that adjustment go as far as trauma? No. That's something that happens in the process and shouldn't be happening. But also, to help them with that adjustment, again, we're here, we have social workers to do that and also that peer-to-peer support. So that's the biggest thing that they say—"We just wish you were here." And I think for us as well, we feel like we're doing as much proactive inreach as we can and we're a bit puzzled that there aren't some standard lines of communication and referrals and connection to us and, therefore, into families.

MELISSA COTTERILL: Yes, I think, if I could just add to that, the medical professionals are giving outdated information to the parents who are expecting babies with Down syndrome and, I guess, it's a breath of fresh air and a bit of a lifeline when they speak to someone who has walked that path before. That's what all of them say. They just want to speak to another parent, just to get that lived experience, because the information that they're being given doesn't reflect the lived experience of families that do have babies or children with Down syndrome.

The Hon. SARAH MITCHELL: Can I go back to something you just said, Ms Caska, about that interaction with Health. Obviously, we've had some Health officials appear and I think we'll probably have them appear again at some point. I think you said—I don't want to put words in your mouth—you're not understanding why it's not easy enough to have your packs available widely. What kind of discussions or interactions have you had with NSW Health about that, as a peak body? Do you know of experiences of other organisations who might provide support for differing but similar reasons to parents who might need that support? Is there any indication why it's hard for you to get that resource in there?

EMILY CASKA: No, not really. I would've thought there would be some sort of precursor, maybe one of the other peak bodies or complex conditions might have an inroad that we don't have and we could dovetail off that and leverage—because I am acutely aware that Down syndrome is a very small percentage of the population. Obviously, it should be bigger, given those termination rates. So how do we make it as easy as possible? We know on the ground it's very hard and busy, so in services that we've designed—but, again, we're fully funding this, and Health are well aware that we run this program. The feedback we get back from the health professionals is, "Five star, come back again and again." We try to tailor it. We know nurses don't have an hour to sit around. We do it when they do their shift changeovers. We make it short and sharp, 10 or 15 minutes, and really approachable.

But when we did tell Health about it, about 18 months ago, possibly something like, "Cerebral palsy or others, is their information in, and is there some way we can corral it all together?", it was like, "Oh no, what you're doing is quite innovative." I probably wouldn't have thought an information pack about Down syndrome is overly innovative. So, no, what we've been told is, "No, there is nothing happening." And then, to date, for us the conversations with NSW Health have kind of ended there. Not long after that, they were doing a review of the Blue Book. That was probably about nine or 10 months ago. We got quite excited about that because they were looking at digitising the Blue Book—great, love that, from the dataset point of view but also for families. If then you can plug that into your dataset, gosh, the digital information that we could put behind that. I'm still a bit old school, I love hard copy as well—

The Hon. SARAH MITCHELL: You can find yours? I can't. Anyway, don't tell my children I said that.

EMILY CASKA: It would be amazing. We got quite excited, but that then didn't progress. So I'm not sure what the barriers are, but all I know is as a peak body we're doing this completely unfunded. I would love to send it out, but we're paying for all the postage. And we literally have our staff, which includes some of our amazing staff with Down syndrome, hand typing a database of where all the hospitals are, and we're trying to purchase databases because we're just not getting those inroads with Health when I feel like we're presenting them with a pretty simple solution. If they could just pay for the printing and the postage, that'd be great.

The Hon. SARAH MITCHELL: That might be, potentially, another benefit out of this inquiry hearing, evidence such as this and—

EMILY CASKA: Yes, and then, again, zooming out from just us. I'm sure there are others in our boat. How do we get that information in? We are well aware that there is a lot that probably needs to get out there.

The Hon. SARAH MITCHELL: Yes. And, as you said, some families at certain times will need services of different organisations depending on their own experience with their own children. Quickly going back to your submission, you called out young parents and their experience, particularly if they do have babies in neonatal care and how that can be severely isolating for them if they don't have support people around them. Again, is there anything in that space specifically that the Committee should be looking at in terms of recommendations for those younger parents who might not have that family support in the same way that, in your experience, would make a difference?

KYLIE PUSSELL: Yes, I'd love to probably take that on notice, if I can, because I definitely think some social workers who work in the neonatal units work a lot more with families that might have higher risks, so I wouldn't feel comfortable in saying exactly. But I think, yes, social workers in the units would definitely have some great ideas around that.

The Hon. SARAH MITCHELL: That'd be great. Thank you.

The Hon. GREG DONNELLY: Thank you all for coming along. At the time, I'm sure you all followed in different ways the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, which obviously ran for a long period of time and published a multivolume report. Like many of my colleagues in the Parliament, I have an interest in this policy area. I followed the royal commission and I want to refer to some of the evidence. This was all on the public record, it is in one of the final reports, so the names are able to be repeated. This evidence was given to the inquiry on 19 February 2020. The witness who is answering the questions is Ms Toni Mitchell, and the person asking the question is counsel assisting on that day, Ms Eastman, SC. I will not read through it all. It is an exchange about Ms Mitchell's experience with a diagnosis and what played out.

During a prenatal ultrasound being undertaken by a technician in a hospital, the technician told Ms Mitchell that she was having a boy. The technician then went quiet and, all of a sudden, rapidly left the room, to Ms Mitchell's surprise. Ms Mitchell was there with her mother and her little son. The technician came back with a group of people, including a senior male, who I presume was an obstetrician or gynaecologist—I'm not sure—or a senior technician. Anyway, he's described as "an older man", for the purposes of the evidence. Now, to quote the older man—this is quoting directly from the witness:

He said, "We also look for soft markers. There's 10 soft markers that we look for at this point, and we can identify that your son has six, and based on this, it's highly likely your son has Down syndrome."

He told me what the six were ...

So he was quite clear about that. He then looked at her and said, "We need to talk about this further." I'm slightly paraphrasing here. Then after a short conversation he simply said to her, "So here's your appointment for a termination," and ripped out the appointment and handed it over to Ms Mitchell. I won't go on, but Ms Mitchell had no intention of having a termination and was completely bowled over by it. I mean, she basically broke down in hysterics, so to speak. Her mother came in to give support and the little boy was all over the place, so it was a really terrible situation.

It just jarred me when I read that evidence in the transcript. I'm just wondering, is that something that you've heard about? If it is, is it something that you hear about infrequently, frequently or moderately frequently? This is the sort of treatment where, out of the blue, there's a diagnostic decision made and then a proposition is put without any engagement, really, about wanting to even talk about anything other than, "This is what I'm saying." This is ripping out the appointment for the termination and handing it straight to her. Can you comment on that?

EMILY CASKA: That is a jarring example. If I was sitting here five years ago, before coming back, I would've been shocked. To me, that's the vast majority of our families, and you do read them. Even just reading

some—I put a LinkedIn post up just last week and another 30 families shared that exact story. You do sit there and think, "How could this happen? Surely this isn't happening in this day and age." The further we ask, it is. And there's a lot in that. There is a lot of sibling trauma in that. That's right: It's not a question. It's a preposition of, "This is the natural next step." It's being told to them by a health professional in front of a group of other health professionals in a very short way, no information about it.

That is absolutely what the vast majority of families are experiencing, and, like I said, it's not just once. If she said no then, she will get it handed to her at the next appointment and at the next appointment. There is judgement and there are attitudes around that as well. It is the vast majority. I think that's why I wanted to make the point clear at the start of this: I'm not talking about 10 families out of my 5,500 members. I'm talking about—it's every single family I'm speaking to. We had a families group in Mudgee last week, who said the same thing. Dubbo families group on Saturday—they're saying the same thing. I walk away as well, going, "How is this happening at such a mass rate?" I'm talking about, I would say, at least 80 per cent of our families have had exactly that, on top of the outdated information and on top of, "This is what they can't do."

The Hon. GREG DONNELLY: Are any of the medical colleges showing preparedness to sit down and talk about the possibility—I'm thinking most obviously of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists but also maybe the college for GPs—to receive and be engaged, or be able to be engaged, and talk about the possibility of the sharing of information that ultimately can make its way through to new doctors?

EMILY CASKA: They haven't proactively reached out to us, which is interesting. Again, I'm a staff of eight part-time parents. That's on my list now. What probably struck me, if I look back at the ABC interview that we did on Friday—RANZCOG were interviewed as part of it, as was a genetic counsellor. What I personally found interesting—and we've had a lot of feedback from families since—while our message was very clear, it was followed up with a genetic counsellor. I believe his statements were, "My role is to meet with families after a diagnosis." I have never heard of the guy, nor have most of my families. Then there was a representative from RANZCOG. Some of the statements that she made that families gave me feedback on over the weekend was her language around, "The clinician and the family make the decision." No, no. The family makes the decision. And, no, we've had no contact with RANZCOG, and that is absolutely a really key part of this puzzle. This isn't just a health issue. It's even the radiologists. It's everyone that's a part of this ecosystem. They all have a role to play. So, no, we haven't had any engagement from them.

The Hon. GREG DONNELLY: Perhaps even with respect to the curricula at the universities used to train doctors?

EMILY CASKA: Step back to that, absolutely. That's part of our recommendations, absolutely.

The CHAIR: That brings us to an end. Thank you all so much for coming today and providing evidence. If any questions were taken on notice or if there are any follow-up questions from the Committee, the secretariat will be in contact. Thank you to both of your organisations for the amazing work that you're doing.

(The witnesses withdrew.)

Ms FIONA O'SHAUGHNESSY, Project Manager, Hygieia Health, affirmed and examined

Dr MARIA DEL PILAR LUNA RAMIREZ, Obstetrician and Gynaecologist staff specialist, Acting Head of Department, Women's care unit, Northern NSW Local Health District, affirmed and examined

The CHAIR: I now welcome our next witnesses. Thank you for coming and providing evidence to us today. Do either of you have an opening statement?

FIONA O'SHAUGHNESSY: Firstly, thank you so much for having us here speaking with you all today. Having an inquiry into birth trauma is long overdue. We are grateful to the Committee for making this happen and hearing us and all the women. We hope that New South Wales has set an example for the rest of Australia and that the maternity care system will be reviewed at a national level. I would just like to take a moment to also acknowledge all the individuals who bravely shared their story in the submission process but also in the hearing, because we acknowledge that bringing up old traumas can also be retraumatising.

I wanted to begin by explaining a little bit about who I am and who I'm here to represent. I am a mum of three boys, a woman who has personally experienced birth trauma. I'm a maternity consumer advocate, a childbirth educator and a doula, in which role I have also witnessed birth trauma and obstetric violence. Today I am here representing Hygieia Health. We are a charity dedicated to preventing and healing birth-related trauma. We are a grassroots, volunteer-run charity organisation. The founders are all mothers and grandmothers, experienced in the birth world, who have a belief in birth as a sacred rite of passage that should be honoured for all women.

We started our dreaming in 2016, as a group of midwives, mothers, pregnant women, doulas, all coming together initially to figure out how to help local mothers access safe, supported births outside of the hospitals that were offering services that local women didn't want. We had a vision for collaborative birth sanctuaries, creating an alternative within the maternity system, specifically designed and operating in a real mother-centred way. This is a vision of true collaboration, with access for women of all levels of risk, offering a homebirth program, supporting homebirth midwives, a birth centre and an operating theatre for emergencies.

We launched in 2020, just before COVID. And during COVID, our focus diverted. Instead of focusing on building that hospital, we filled a necessary gap and focused on offering crisis support for all of the women who were excluded from care or who struggled with partners and families being excluded from their births. During COVID, we really saw where mothers and babies, and particularly birth, sits within the hierarchy of what our Government deems important. During restrictions, there were 10 people permitted at a funeral, five at a wedding and zero to one at a birth. As restrictions lifted, stadiums were open so that people could watch rugby, but women were still birthing unsupported or having to choose between their partner and doula. In addition, women were isolated from postpartum support and care and family and community support at a time when that is so vital. Through this, women really saw that they, and their entire perinatal experience, were at the bottom of the priority ladder.

Women and families who were journeying through their pregnancies and births were treated abysmally. This led to a whole other layer of birth trauma that was already compounding for women in an unsupportive system. Women were not prepared to go to hospital to labour on their own, and private midwives were inaccessible, either through being booked out, affordability or access. Freebirths that were not planned to be freebirths were on the rise. After COVID, we refocused on birth trauma awareness, healing and support. We have been refocusing on our original dream and delivering education, resources, events and trauma-informed training for midwives, obstetricians, doulas and women.

We are altruistic and ambitious, and we work off the mindset of "If not now, when? If not us, who?" We are dedicated to listening to women and offering support to birthing families. But being a volunteer-run charity, we are under-resourced and lack the funding to make the real change we think is necessary. We look forward to working with the New South Wales Government in the future to support our commitment to the women and families we serve. We are aware of the BHI research that has been referred to throughout this inquiry that indicates that a large proportion of women are experiencing positive births, yet we are also aware of the alarming statistic that one in three women experience birth-related trauma. And we have our own stories—those of the women we are connected to and people coming to us with their experiences since we started our organisation, and especially during the submission process—indicating to us that the number is probably higher.

Sadly, we also know from research that 70 per cent of birth trauma is iatrogenic, which means that 70 per cent of it is preventable. The root cause of this issue is often due to factors such as burnout, stress and overwork. Such stress hinders one's ability to provide compassionate and respectful care, which can lead to traumatic experiences for both the mother and the baby. We aim to bring attention to this problem and support midwives and obstetricians by providing better resources and education. We are committed to assisting them in

healing from their own traumas, biases and unconscious beliefs and behaviours. Through our work, we have come to see that we are not at a point with maternity services in Australia where we're in a position to "blame" any one particular profession. We can see that this is a systemic issue and one that we feel requires a complete overhaul of the system.

When you look at the research and the effects of trauma cohesively, you can see how far the trauma reaches. It is not just the woman who experiences something traumatic on one day of her life, like with a car crash; it is long lasting, and it affects the woman, her hormonal make-up, her neurobiology and her relationship with all of the people in her life, including with her baby. It also affects the babies, the partners, the care providers and the entire community. Although this is outlined in our submission, we would love to see enhanced training and education, improving the understanding of birth trauma, trauma-informed care and evidence-based practices among healthcare professionals to foster more respectful and compassionate birthing experiences. We'd also like to see subsidised antenatal education classes for couples outside of hospitals; women-centred midwifery care that is accessible for everyone, which means all risk; care that recognises the unique needs and preferences of women; and investment in models that prioritise personalised care and shared decision-making.

We'd like to see culturally and linguistically appropriate care for women, especially Birthing on Country models; informed consent for all women in all situations; implementation of continuity-of-care models all over Australia; and publicly funded homebirth programs in all LHDs, taking the births out of the hospital and into the home, and utilising the hospital in the small number of occasions where it's necessary. We feel that this would lead to lower intervention rates and would actually be cheaper for the health department overall. Birth is not a medicalised event, yet it is increasingly becoming one.

We'd like to see an expansion of the availability of birth centres where homebirth is not a preference; respectful and supportive care for all types of birth, inclusive of early pregnancy loss, stillbirth and abortion; funding and support for postpartum care, including birth debriefing, counselling or therapy; Medicare rebates for lactation consultants, women's health physios or other follow-up care; funding for in-home care and support, such as postpartum doulas; funding for facilitated mums and bubs groups or women's circles; and a review of best-in-class models of care all around the world. Thank you for taking the time to consider our submission and for inviting us here today to give evidence.

MARIA DEL PILAR LUNA RAMIREZ: Thanks for giving me the opportunity to be here today. I feel proud to live and practise in a country that has the insight and willingness to look into this important matter that affects us all. I believe that continuity-of-care programs that include birth for women of all types of risk, and provision of choices that involve publicly funded homebirths, are truly the cornerstones of reducing birth trauma. If the time I dedicate in this statement had to be proportional to the urgency and the magnitude of the solution, I would dedicate 95 per cent of today's time to reiterate these concepts. But I believe the Committee has had exposure to them by all of the mothers, consumer representatives and professionals who have talked before me in this inquiry, hence I would like to focus on other aspects that play a key role into the complex equation of birth trauma. I will expose this briefly in five points: education on rights and body autonomy to all women; birth trauma prevention training; debriefing clinics; caring for the health of our workers; and guidance for professionals caring for women requesting "care outside of the guidelines".

On education on rights and body autonomy, it is every woman's right to decline medical information or management if this does not align with her beliefs of what is best for her own pregnancy. Declining parts or a whole plan of care or birthing out of the hospital does not go against the law. Many women are unaware of that. This concept should be explored in depth at the first antenatal visit and revisited as many times as necessary. Continuity of care that includes birth provides the right environment for women to feel safe to express their preferences and increases the chances for women to feel heard and respected on their wishes.

Birth trauma prevention training is not a core part of the training of specialists in the country. I know that the Royal Australian and New Zealand College of Obstetricians and Gynaecologists is currently looking into how to incorporate some of these concepts, but much more is needed if we want to see a significant impact in a timely manner. Birth trauma prevention and management training should be designed by experts on trauma, in collaboration with birth workers, and should be made part of our regular professional requirements for the length of our entire career.

Debriefings are an initial step towards healing for many of the affected women and families, yet we have never received formal training on how to conduct those, how to provide a safe environment and how to identify when we, the professionals, are feeling emotionally unsafe or triggered, and how to manage it. Debriefing clinics where women have access to not only medical input and space to provide feedback but can also receive psychological help from counsellors, psychologists or psychotherapists is needed. A formal process to share the feedback and the lessons learnt with all colleagues should be part of the process.

Health workers are constantly exposed to high levels of stress. We are often overworked, usually due to understaffing, but we are also stressed due to the very nature of what we do. This is more acute in rural areas, which often have little attraction for professionals. Living on a constant baseline of stress does not place us at the right status to be able to listen and adapt to the needs and desires of every woman. Many midwives leave the profession because they cannot practise the compassionate and personable care they dreamed of offering. I know many colleagues, midwives and obstetricians whose lives have been shattered by a bad outcome, yet we are all expected to show up to work the next day and to provide compassionate care for a different mum. Stress leave or the need for psychological support is seen as a failure to cope, rather than the logical consequence of the work we do. We need to create a work environment where regular psychological support is scheduled and expected, rather than the exception.

On guidance for professionals, we are facing more and more women and families who request what we call "care outside of the guidelines". That means they request a model of care or management that is not the first choice recommended by official scientific bodies or some of the current evidence. It is paramount that a woman can be respected on the wishes around her pregnancy care, yet there is a lack of support and guidance for many of these situations. Can we support their choices without failing our duty of care? Will I lose my job? Will the hospital support me if a bad outcome happens? If a woman declines to be monitored, do we have to keep offering it at regular intervals or can we respect her desires and wait for her to request assistance? How much is too little or too much information?

We are accused of fearmongering if we provide information around all possible bad outcomes but, on the other hand, we are accused of not have provided information for women who have experienced a complication, even though they had no particular risk factors for it. Where are the limits of the information we should and should not provide? As a conclusion, I strongly believe that a key step in the right direction would be to appoint a commission—a taskforce for birth trauma prevention and management—where consumers, professionals at the coalface and policymakers can meet and redesign care so we can do better by our staff and the women we care for.

The CHAIR: Dr Maria, I know you've covered a little bit of this already in your opening statement, but in your submission you talked about the current medical culture and how it can contribute to birth trauma. What are the key contributing factors here?

MARIA DEL PILAR LUNA RAMIREZ: I think that the lack of continuity of care is one of the main factors. If a woman or a family were seeing continuously the same person, there would be no need to repeat themselves. They would trust that their desires would be respected because they're seeing the same person that already has agreed to do that. By all means, the continuity of care and guidance into how to provide counselling, debriefing, respecting their desires and legally what happens if they decide to do something that is different to what is stipulated in the guidelines—I think that, definitely, the professional would feel much more backed up and able to provide the care that the patient is requesting. That backup, that guidance, does not exist at the moment.

The CHAIR: We also heard today about women being risked out of homebirth programs, and we've heard previously about women being risked out of midwifery group practice. You say that they're the ones needing it most. Can you explain what the problem is here? Why is that happening and how do we fix that?

MARIA DEL PILAR LUNA RAMIREZ: It depends on the different States, and Australia is not uniform across all the States. But in many States, the midwifery group programs are designed for low-risk women. That is to say there is a body or ministry, NSW Health, that declares what is to be low risk or high risk, and the continuity of care programs sometimes are offered only to the low risk. This does not need to be like that. I've worked in the Northern Territory, for example, where we have an all-risk model of care. That means that there are midwifery group programs for low and high risk, which actually are obviously the ones that need it the most because they are the ones that are at the higher risk of developing a complication and the ones that need the most continuity of care. That said, I think that every woman and every family that desires so should have continuity of care. It's just about the concept that continuity of care should only be for a certain group of women with certain characteristics. This is the gold standard and this has been proven again and again in multiple studies, so why are we not implementing this for all women and all families?

The CHAIR: In this question I want to talk about rural and regional areas, and I know that you are working in Lismore. But you also talked a lot about the healthcare professionals, as well, and the lack of support, understaffing and under-resourcing. Can you talk about how that particularly affects regional and rural areas and how that links to birth trauma?

MARIA DEL PILAR LUNA RAMIREZ: No-one shows up to work wanting to produce trauma or wanting to aggravate trauma. I don't know anyone that does that in any related birth worker profession. But, yes, there is very little attraction to work regionally, currently, in New South Wales. The award doesn't permit any

distinction between whether you work in metropolitan areas or in regional areas, and in regional areas, in general, we struggle to fill our positions as obstetricians. There are many rural hospitals that are not able to fill the positions of the specialists and have to revert to VMO models or to have continuously professionals—what we call locums. They're someone that comes for the day, for the week or for the month and then is paid by the day. You can't build anything significant or meaningful with someone that comes for the day or for the week, and this happens also for midwifery.

We need a reform in the system that makes going regional more attractive—for families to relocate regional or for specialists to relocate regional. Being overstretched, overworked, frustrated and with a lack of support doesn't place anyone in the right state of mind to be compassionate, to go the extra mile, to listen to anyone, when you have to cover several works in the same day—when you are asked to be overstretched yourself. If we want to provide quality of care, we have to have quality of life as well. I guess it's a basic concept.

The CHAIR: You also advocate in your submission for debriefing clinics. I just want to hear a bit about how you think that those debriefing clinics would operate and if there's anything that currently exists in Australia or overseas to help us get our heads around how those would function.

MARIA DEL PILAR LUNA RAMIREZ: I can tell you how it works in my hospital because we do have debriefing clinics. The way it works is either we—in northern New South Wales we have a QR code that is given to every woman after birth. It doesn't have a time limit so, whether you have birthed in the last month or in the last five months, you can scan the QR code and it will give you the pathway to give feedback or complaints or to request a debriefing. This comes to the midwifery unit manager, so that's one pathway through which women and partners can request a formal debriefing or just provide feedback.

Sometimes the midwife in the unit can send me an email saying, "We were present at the birth of this woman and, by knowing her, we thought that she may have some level or degree of trauma and that she would benefit from a debriefing. Would you mind getting in contact with her?" I receive letters from GPs saying, "I have seen this woman postpartum and she's mentioned having the benefit of having a debriefing." Those are the three main pathways that I receive debriefing referrals.

I have a clinic that is only led by myself at the moment, and they have about one-hour to 1½-hour appointments. In general, I ask them what would they like to have out of that experience. Sometimes women want to fill in the blank spaces—they don't remember what happened or why it happened. They want to hear the medical reasons why or why not it happened. Sometimes they just want to give feedback about a traumatic experience and say, "This that happened to me should not happen to anyone. Can you please take note and pass that on, if that's appropriate?" Sometimes they just want to be heard and held in their experience. They just want to be heard; it's as simple as that.

There is no MBS code for this, so that's one thing that needs to change—to create the debriefing clinic and for Medicare to be rebatable or for there to be activity-based funding. Also, we need extra funding. This is a very time-consuming and emotionally exhausting activity, so we need support. We need psychological support. I am not a psychotherapist or a counsellor; I am a clinician. I can fill in the blank spaces, I can show all my compassion for what happened, and definitely what I do is take feedback and incorporate that into our practice. But these women also need psychological support that we are not able to offer to them.

The CHAIR: You note in your submission that patients cite feelings of not being respected in their bodily autonomy as one of the causes of birth trauma. How can we better promote informed consent in that birthing process?

MARIA DEL PILAR LUNA RAMIREZ: I think that a key step would be at the first antenatal visit. Usually they have a one-hour walk-in visit with a midwife via phone, and then they will have another one face to face. I think that that is the first step—to inform women and families that they have the right to decline parts or the totality of an intervention that has been proposed. They can decline information. They don't have to sit there quietly and listen to what we're saying if they don't want to. I think that that would be a very important step because most of these women and families that get traumatised do so because they didn't know that they could decline care.

I have an uncountable number of women that have debriefed that they didn't know they could have said no to what was proposed, and hence they feel that they failed themselves. They didn't advocate for themselves and that haunts them forever—the fact that they didn't know that bit; they never were told. They thought that it was illegal to birth at home if they wanted to do so. They thought it was illegal to decline a caesarean section when that was what was recommended. So I think just working on that concept—you have the right to decline care and you have the right to choose and pick whatever we are offering; it's your body and you can choose—would already avoid an important part of the trauma.

FIONA O'SHAUGHNESSY: I was just going to add to that, because informed consent is actually a basic human right in childbirth. It's listed in the basic Human Rights in Childbirth declaration. Sometimes the issue is that they don't know that they can say no. They're not given that option. What is actually legally required of care providers is to give them all of their options, including all alternatives, one of those alternatives being that they can decline, which isn't being done. I can only speak from my own personal experience in witnessing birth in some of the hospitals that I've worked in, and often that consent, while it's verbally given, is actually coerced out of them. It's not necessarily that they've been given the option to say no; they've been bullied into it to eventually say yes.

Dr AMANDA COHN: I just have a couple of follow-up questions from your line of questioning, Chair. The first one is about continuity of care for higher risk pregnancies. It is certainly something we have heard that there is a lot of demand for, and it makes sense that it should be able to be provided. You mentioned the model in the Northern Territory. I was wondering if you could provide more detail of how that works. There must be a system in place for those midwives to get advice or secondary consultation from an obstetrician. What are the nuts and bolts of how that works?

MARIA DEL PILAR LUNA RAMIREZ: It works basically exactly the same—that they're low risk. Every midwifery group practice also has an obstetrician allocated, so even though they cater for low-risk women, they have an obstetrician that cares for that group of women. So it works in exactly the same way. They provide care. It's just that when there is a higher level of risk they need more interaction with the obstetrician. They need more questions. They need more reach to the obstetrician to say, "This is what's happening." Midwives do midwifery, and obstetricians do the higher risk part of it. For the midwife, there is absolutely no difference whatsoever. They do midwifery. They work with the woman, they know their wishes and they are the ones that are in the best, most privileged position to tell us what the actual woman wants. What does she want? What has she expressed to you are her preferences? Because they spend much more time with them, that places them in the perfect place.

The way it worked in Darwin—I think that they said in no other place in New South Wales they have an all risk MGP model. I don't know if Belmont is the one, but I believe that they said no other midwifery practice has an all risk model. So we divide in different groups. It doesn't necessarily need to be like that, but the way that it was in Darwin there was a psychosocial high risk, there was a structural anomalies or twins high risk, there was the remoteness high risk and there was the homebirths—all of those who wanted to attend the homebirth with publicly funded midwifery. And then each group could have an obstetrician allocated that mixed regularly with that group of midwives. We go through every case. They have the opportunity to ask any questions, to expose the results and to expose the wishes of every one of their patients, and then we make a plan in agreement with that. Sometimes you need to see physically those women. Sometimes it's just the advice you pass to the midwife and the midwife discusses some of them with every patient. So it works exactly the same, just with a little bit more interaction with the obstetrician.

Dr AMANDA COHN: Do you know if that model in the Northern Territory or the one in New South Wales has been evaluated?

MARIA DEL PILAR LUNA RAMIREZ: I would imagine that the Northern Territory must have been widely evaluated, yes.

Dr AMANDA COHN: Feel free to take it on notice. I would love to know if that has been written up.

MARIA DEL PILAR LUNA RAMIREZ: I will take that on notice.

Dr AMANDA COHN: My other question would be about feedback from the doctors or management working in that model. We have asked about it at a couple of other hearings of this inquiry, and there are some barriers to a hospital providing that—whether they're real or perceived—to do with the training of junior doctors and that their rostering for continuity was too difficult because of the needs of the training program for ONG registrars. I would love to know how they manage that in the model that you are describing.

MARIA DEL PILAR LUNA RAMIREZ: Continuity of care for doctors is very challenging just because of the very nature of what we do—the much smaller numbers, and we are constantly pulled in different directions. If you are training you need to go to theatre, you need to go to clinic, you need to do several things, so it's not assured that you're always going to be seeing the same patient. That's why it is so important that we ensure that the continuity of care is provided by the midwives, so they have that point of continuity of care, with us being just in the background advising when or if the risk arises. I don't even know if it is desirable or not or possible that a doctor provides continuity of care in the public system. Obviously, in the private system, it's a whole different thing, but midwives are the experts of physiological birth, so, by all means, I think that they should be the primary

care providers for all or most women with the advice of obstetricians if it needs to be. I don't know if that answers your question.

Dr AMANDA COHN: It does, absolutely. The other thing I wanted to ask you about that came up earlier in our hearing today was the issue of difficulties transferring homebirth patients when the need arises. We have heard some evidence about challenges for private practising midwives getting the agreements that they need with hospitals to be able to provide that care safely. Do you have an understanding from your colleagues of why doctors are not wanting to engage with those arrangements?

MARIA DEL PILAR LUNA RAMIREZ: I think it's nothing to do with us. I think that's come from NSW Health. I don't have any say on whether or not we have continuity of care from private midwives, in my department at least. I think there are two different problems. One is that private midwives, to my understanding, need a collaborative agreement with an obstetrician which, in fact, only can be provided by a private obstetrician, which means that the woman has to pay the private midwife and the visit to the private obstetrician. So that just increases a little bit more the cost. That's one barrier, while women that are low risk when it comes to midwifery clinics don't need any agreement of the obstetrician. They are low-risk and they are cared for by the midwives, so I don't really understand why the women that are low risk in the private midwifery role need a collaborative agreement with an obstetrician when they don't need it in the public system if they are low risk. That's one problem.

The other problem is the lack of agreements to allow private midwives to continue their care when they come into the hospital. That's the lack of admission rights. Private obstetricians may have admitting rights into a hospital, so when the patient comes into the hospital they can come, see and treat. That exists in very few locations with midwives, and I don't see why it could be any different. Midwives have regulations. They have the Australian College of Midwives and they have rules they have to follow. So I don't understand. They are regulated, so why cannot they have admitting rights in a hospital? Why cannot hospitals offer this to midwives? What are the barriers? I can't comment on that because obviously that's a medical admin issue. I'm sure that it has a lot of challenges, perhaps, but those challenges have been surmounted for obstetricians, so why cannot we do the same with midwives?

Dr AMANDA COHN: Picking up on the debriefing clinics again, that's obviously quite a specialised skill to be able to provide. At what point in training do you think that doctors should be upskilled in doing that as part of their specialist training? Is it post-fellowship continuing professional development? Is it at medical school?

MARIA DEL PILAR LUNA RAMIREZ: I think the medical school would be a really good point to start with, because how to talk with a patient affects all specialties, not only obstetrics. It is true that birth is a critical moment in a woman's life in general, so I do think obstetricians, by all means, should have specialised training during their registrar years into how to provide that safe environment; how to debrief; how to assess the choices that a woman and a family want; and how to provide guidance without being coercive. This should be provided, definitely, during the training years, but I think there are many professional requirements that we have to meet every year. There is the professional continuance, professional development, and there are CGT trainings. There are many things we need to comply with every year, and I think this should be one of them. We do one entire day of prenatal safety per year. We do CGT training every year. There are different fields that we have to tick in the box per year, and I think that communication, when it comes to a moment that is so vulnerable for a woman in a family as is birth—I don't understand how this is not already in a training program, but I hope they will.

The Hon. SARAH MITCHELL: I just wanted to pick up on the issue of postpartum support because that is something that you both spoke about in your submissions and it comes a little to the questions asked by the Chair to you, Dr Ramirez. You were saying how sometimes you need time and funding to be able to have these conversations. In your submission you talk about specific debriefing clinics with a multidisciplinary approach. In your submission as well, Ms O'Shaughnessy, you talk about increased funding and support for postpartum care. If money was no object and we were in an ideal world where we could give women and families everything that they needed—especially those in regional communities, because that's close to my heart—what are some of the models of care in terms of a debriefing clinic, or how would you envisage something like that to operate if it was something that we could make happen? I am happy for both of you to comment on that.

FIONA O'SHAUGHNESSY: I think in terms of holistic postpartum care, a really good case study to look into would be the model that exists in the Netherlands. After a woman gives birth in the Netherlands it is a mandatory requirement that she gets 50 hours of a postpartum doula over the course of, I think, a few months after birth. She has always got someone who can come in and support her. They are connected to the hospital and medical system that then can refer them on if they need lactation support, women's health physio, if they need psychology support or even support with day-to-day tasks like cleaning and things like that around the house if they're struggling with multiple children or birth injury or anything like that. It's a really good model to look into.

If money was no object, then I would have a dream that we would have postpartum doulas for every woman in New South Wales or Australia that then could be funded by the government, because at the moment they are a privately purchased service and a lot of women can't afford a postpartum doula, especially with the rise of the cost of living and being on a single income once their babies have arrived. There is a narrative I suppose that postpartum doulas are kind of a bit of a luxury and that all the things that you need for the baby, like the pram and the carrier, that's a priority but looking after the mother isn't. If money was no object, that would be one thing.

The other thing that I think we would really like to see is funding for all women to access a women's health physio after birth. I still see a women's health physio after my first birth seven years ago. I still have ongoing problems, but I have to pay for that out of my pocket. One of the things that I often talk to my women's health physio about is, if women were given funding or were even just able to see someone quite soon after birth, it would actually save the health system a lot of money later because women wouldn't be having to go in and get surgery at age 60 as well as all the mental health stuff.

On top of the women's health physio, access and support to debriefing clinics either within the hospital or also independent ones where sometimes women don't want to go back to the hospital setting that the trauma occurred in. They need to be given the option. You have to be quite savvy to understand that you can go to your GP and you can get referred for a women's health physio for a certain amount of visits—I think it's five—only if you have other issues. With mental health, you can get 10 sessions. It's still an out-of-pocket expense. There is a huge amount of women and families, not just the women, who have experienced trauma but have absolutely no access to even the gap that they have to pay to be able to access those services, and they don't even know that they can ask for it.

The Hon. SARAH MITCHELL: Yes, that they exist.

FIONA O'SHAUGHNESSY: Yes, so a whole range of holistic services. Also lactation consultants are an out-of-pocket expense. Lactation consultants are worth their weight in gold yet they are an out-of-pocket expense, so there is a number of women who struggle with breastfeeding. They struggle unsupported because they simply can't afford or can't access lactation consultation and haven't got the support. You just have to look at a couple of studies to look at how important breastfeeding is for the health of the child and for their overall immune system, which again would save the government lots more money later on in life when the children aren't sick all the time with different things.

The Hon. SARAH MITCHELL: Did you want to add to that?

MARIA DEL PILAR LUNA RAMIREZ: I think that if money was no object—that's a beautiful thought—

The Hon. SARAH MITCHELL: Isn't it.

MARIA DEL PILAR LUNA RAMIREZ: —it would be marvellous in the public system—I think that every woman would have a midwifery continuity of care or would belong to that, and every MGP midwife could have enough allocated hours so they could see this woman in the postpartum period as many times as needed. One of those visits would need to be a two-hour debriefing on the birth experience. That would need to possibly happen by default. The woman can opt out but it's not an opt-in. It's an opt-out choice, so all of them would have the time and the wages and affairs to offer that to the woman, and also to have the insight to say, "This has not been enough. Let's retouch base in six months."

Many of these women by the time that they see their birth providers, even if it's an MGP midwife, are truly and well into the newborn bubble. They are busy, they are adapting, they are not sleeping, they're having troubles with lactation, they are not in the right state of mind to analyse what happened and what didn't happen. So maybe what needs to happen is that that debriefing may need to happen at a month, at six months or a year, or a phone call, to follow them and then see what's happened. I sit with many women that are still traumatised about things that happened years ago; they have never talked to anyone about it. That's what I would propose.

The Hon. GREG DONNELLY: Thank you both for coming along; I appreciate it. Dr Del Pilar Luna Ramirez, I have a very interesting point that I would like to follow-up, if I could, please, on the matter of the provision of information to women and the issue of if they don't wish to receive information. My reading of the evidence we've received—and as you know there have been many, many submissions and many have come along that provide oral evidence—is that there's a criticism thematically that runs through many of the submissions. The oral evidence is a criticism of lack of information, generally speaking, from really when they find out that they're first pregnant right through to birth and beyond birth. So if one takes that period—I won't put an end point on it but a significant period of time—the constant complaint, and I use the word "complaint" because I think it's reasonably legitimate, is of not having information provided to them to, as they describe, be able to think it through and be able to make a decision about what to do in their interests.

My question is that I thought that you were putting the argument—and correct me if I'm wrong—that there is this sensitivity or there is this issue of being able to not receive the information if they don't want to receive the information, and I accept that. But I'm wondering in practice though, how does one, I guess, identify that an individual doesn't want either information or part thereof? Because, presumably, a number of matters are being discussed concurrently as it's being talked through and the whole complexity of it. How does one know to perhaps stop at this point and not cover this but there may well be this other element that in fact there is a real appetite for information? How is that navigated?

MARIA DEL PILAR LUNA RAMIREZ: Very difficultly because we also have to take into account the constraints of time. I don't have endless time in a public clinic. I may have 20 minutes or 30 minutes, which is already a privilege if I have 30 minutes for a woman. I guess that continuity of care comes and strikes again. If I knew this woman and this family, I would have had multiple occasions to go through their concerns, what they want to know and what they don't want to know. If this woman is seeing a different provider every time, she has to start from zero in a way. Every woman's needs are different. I guess sometimes we have to start a relationship with a woman saying, "Today I would like to discuss this and this and this and this. Does this resonate with you or is there anything else you wish to discuss today?" Because for me it's important, and it's not necessarily her first priority.

We have a duty of care to provide information if they wish to receive it. So I think it's important to state that openly in the beginning of the consultation. "This is what I would like to discuss with you today because you are 36 weeks and you have this risk, and these are the things I would like to discuss. Is that okay? Can we discuss this or is there anything else that you would like to discuss instead?" Then we make the logistics of, "Okay, we have five topics to discuss and we have no time today. Let's pick three and let's make another appointment to discuss the other two," so women can feel that they are heard, that they have time, that they can choose what they want to discuss.

Some families choose not to have information about a particular topic because they believe that we are fearmongering and that that doesn't apply to them. It is their right not to want to hear about a particular risk, and that's why establishing the relationship with them is important, so I get to know, "Okay, for you the most important information is about this." For some women it is avoiding an instrumental birth. For some women it is having support for breastfeeding. Some families and women have a topic that is extremely important to them. The fact that it's not medically very important for them at that point, from my point of view, that doesn't make it less important. It's important for them. We have to allocate a time to discuss it to the length that they feel satisfied with the information. So I don't have an easy answer for your question. It is very difficult to describe to a certainty which topic to talk to, which topic not to talk to and to satisfy their needs.

The Hon. GREG DONNELLY: Can I ask you this question as a follow-up? And please, if you wish not to answer it, say so. Are you sometimes challenged where you think there is a piece of medical knowledge, medical information or scientific information that is important to communicate, from your vast experience and the knowledge of medical science, and there might be resistance or a lack of desire to hear it at this point, but you know, as someone with a lot of experience, that later on down the track it may well be something that will be very useful to know? Is the way that you would deal with that to, perhaps, circle back to that later on? Is that the way that might be addressed?

MARIA DEL PILAR LUNA RAMIREZ: I guess we can only offer. I can only say, "I feel that this is very relevant to you at the moment, and this can have serious implications for your health or the health of your baby. Would you like me to continue exploring that today or would you like to explore something else?" Then it's back to them.

The Hon. GREG DONNELLY: I appreciate that. This is my final question, because I found the reference to the QR code very interesting. One of the ongoing criticisms in this inquiry directed at the way in which birth and the period beyond birth are managed is the lack of follow-up, tied back to the continuity of care discussion you've raised, which has been very well executed throughout the inquiry. I think you said that QR code has been in place for a period of time in NSW Health?

MARIA DEL PILAR LUNA RAMIREZ: We just started in mid-2023, so it has been eight months, maybe.

The Hon. GREG DONNELLY: So it's early days, but can I ask you this question? To the best of your knowledge, if a woman was in that period after birth—let's say, two months out—and having some type of really strong, dare I say, crisis or feeling or whatever, over whatever the issue might be, can she contact NSW Health through the QR code? I don't know whether it is a hotline or she goes to a website, but can she express her condition and seek medical assistance, and will that then be followed through? Is that how it works?

MARIA DEL PILAR LUNA RAMIREZ: It's not for medical assistance. It's more for feedback and requesting a debriefing. If what she needs is medical assistance, obviously it is the GP and the emergency department.

FIONA O'SHAUGHNESSY: It's a really great thing to have them, but it's also not a perfect system either, because a lot of women are given that QR code maybe when they leave the hospital, or they see it somewhere at one of their appointments with their midwife. Then it's often cast aside in chaos of having a newborn baby. There's not a lot of access to it. There's not a lot of exposure to the fact that this service exists. And there's also not a lot of staffing for it to even be operating on a mass scale. The pathways to this kind of debriefing clinic are not that clear. Although we're trying to make it clear, it doesn't always filter down to the women.

The Hon. GREG DONNELLY: Not having that opportunity to have those debriefs has been regularly prosecuted as a concern. It has been a theme right through the inquiry.

The CHAIR: I have another question for Ms O'Shaughnessy. You mentioned in your submission the over-medicalisation of birth as being a key factor. Can you talk a little bit more about what you mean by over-medicalisation and how that's related to birth trauma?

FIONA O'SHAUGHNESSY: Sure. I think there is often an overall cascade of intervention and people being exposed to interventions or medical events in their pregnancy or birth that are unnecessary and that then cause trauma because they look back later. One key example is induction. The latest *Mothers and Babies Report* indicated that the rates of induction have increased significantly, yet the rate of babies' lives being saved has not increased. That indicates to us that we're intervening too often, too soon. It has been discussed a lot in all of the other inquiries, but when you are induced, you're more likely to experience much more painful labour.

Usually, that then means that you are exposed to a lot more interventions that might have been completely unnecessary if you were just given the space and time to allow your baby to arrive in the physiological way. We're not saving any more lives. We're also over-testing. We're forcing women to do tests, like the GBS swab, for example. That's not something that's mandatory in Queensland. That's not something that's even offered to women, but here it is. The course of action is that if you test positive, you then are strongly recommended to have antibiotic use during labour, which affects the baby's microbiome and health after birth as well. You might not even be positive when you go into birth, so it's a treatment that is given that might be unnecessary.

There are lots of little factors like that that we feel are pointing to this over-medicalisation when, really, women are the experts of their own birth and their own babies. Yes, we have this great maternity system that we can access if and when we need it but, realistically, birth does not have to happen in a hospital. We can see from the evidence that, with continuity of care and with homebirth programs or midwifery group practice, there is a lot less intervention because that woman has been able to journey through her pregnancy not just talking about her wishes and hopes for her birth but also understanding her emotional and spiritual needs, as she's moving into the birth space.

The CHAIR: One of the arguments that some witnesses have put forward is that the reason why there are more interventions is because there are other factors, such as women giving birth at an older age, for example. Is it that we are increasing unnecessarily or are there other factors at play? Or is it a combination of both? It's like we're hearing two different stories.

FIONA O'SHAUGHNESSY: Yes, there are obviously women who are giving birth later in their life. So there are increased risk factors. But, as I said, the *Mothers and Babies Report* doesn't show that we're saving any more lives. What that does show is that we've got one in four women experiencing an episiotomy and less than 50 per cent of women able to labour spontaneously. The outcome is that no more babies are being saved but women are being left traumatised and having to deal with either birth injury or birth trauma. We're intervening much too soon. Another intervention that's happening unnecessarily is with IVF. You're risked out automatically. I've had a number of clients who have had IVF babies and they can't access a homebirth program or MGP. They are told from five weeks pregnant that they need to be induced. It's not based on any evidence. There are a lot of situations where women are being strongly encouraged to have interventions that are unnecessary, and the evidence doesn't support them.

The CHAIR: You might have more to add to that, but I have another quick question. What is the reason for the increased interventions? Is it that there aren't enough beds available? Is it a nervousness around litigation? Is it a combination of factors?

MARIA DEL PILAR LUNA RAMIREZ: I would say it's certainly a combination of factors. Women having babies in 2024 are not the same as women having babies in 1950, for sure. The age of the average mother has increased. There is smoking, there is increased BMI. There is assistive reproductive technology. There are many things that play a role in the change of risk that we are exposed to. The evidence changes continuously. We

can't treat the evidence as, "This is set in stone and this is like it is." You have an idea of pregnancy, your risk is like this. No, I can show you that in five years, there's going to be another study that is going to say something different. I think that this needs to be communicated to patients, "This is the current evidence. You may choose to follow it or not. These are the numbers." The numbers speak different to everyone.

Far from me to tell someone that needs an induction of labour or a caesarean section—I think the paradigm is different. The paradigm is we have to learn or relearn to put the decision, with guidance, into the hands of the woman and family: "These are the numbers for your particular situation now, okay? You have a risk of one in X of having this infection for your baby," for example. That risk may change. That evidence may change in 10 years time and we may discover that what we were doing 10 years ago was not right and it now has changed. I think that exposing that to families also makes it less of this is set in stone.

But I have a duty of care to guide you into what the current evidence is and what the guidelines from the college are, to give you the numbers that they give to us and then guide every family and every woman into what are those numbers. What is the one in 100 number? What is the one in 1,000? What does that feel like? For some women and families, one in 1,000 will be a very clear image in their minds, and for some of them not. Some women, you say, "That is the risk"—yes, but that will offer very small risk; it's still a very small risk. We have to be very careful with the language that we use. We need to be taught how to do that, how to provide that information in an objective manner that brings the responsibility back to the person that is pregnant and is going to have a baby.

The CHAIR: I also wanted to ask both of you about hospital policies and protocols and how they might actually impact informed consent, in the way that the hospital's actually running. We have heard a little about this in some of the other hearings, but I wanted to hear from you both around how that's currently impacting.

MARIA DEL PILAR LUNA RAMIREZ: I think that's another area that we have never been properly taught as clinicians: What constitutes an actually valid informed consent? Having a signature on a paper, it is not informed consent. That is the pervasive belief in the medical culture: You have a signature on a piece of paper, that's it—this is informed consent. It is absolutely not. This is a legal concept. You have had time to assimilate what you have been explained. You have made your questions. You understand the risks that you have been explained and you agree or disagree to have the procedure that you have been offered. Again, the lack of time and the lack of continuity makes it that that is actually, most of the time, not possible. To have a proper and valid informed consent, you have to have access to the whole information—the data, the space for questions—which most of the time does not happen.

FIONA O'SHAUGHNESSY: I think this is where independent childbirth education plays a really important part. They actually have time to talk about all the different interventions and why they might happen, and the different situations where that might happen. In independent childbirth education classes they also talk about informed consent and what the woman's legal rights are, so they have the opportunity to explore a lot of possibilities. They also then have the opportunity to go away and write a birth plan or birth preferences, so that they can really outline what is important to them and what they've thought about and what they haven't, which they then can take to their care providers and have a discussion around.

I think one of the challenges is that, first of all, with childbirth education it is also an out-of-pocket expense. It's not publicly funded or accessible to all women. The other thing is that, a lot of the time, care providers like midwives or obstetricians with those appointments may only have five to 10 minutes—maybe 15—in that room to really go through all the different aspects of a woman's birth preferences. It is not really possible. In a situation where something has arisen, it's a little bit like the question is—they're not given time. I've heard a lot of things mentioned in previous sessions that it has to be a quick decision. But with birth, it's very rare that you don't have some time to talk about or to think about what it is that you're consenting to—so just giving them some information and leaving the room and giving them some time to talk about it.

There's only a very small percentage, a really tiny amount of people where it is a very acute, very emergency situation. Aside from that, because the woman and the family are in the hospital for a period of time, there is time for the midwife or the obstetrician to start to talk to the woman about the potential of risks or the potential of intervention and what that might look like. There is always time—it might only be 40 seconds; it might be five minutes, half an hour—to be able to give the woman and her family some time to actually sit with that, to talk to her doula, to talk to her partner and actually really think about whether they have any more questions and what they'd like to do. There is always time for that.

If we also empower the care providers that they have protection against that, too, so that they know they can give that, but also giving them the education and resources to actually understand what informed consent means—as far as I understand, and I'm not an obstetrician or a midwife, it's not a topic that's really covered in their training in great detail. It's just kind of like a ticked box, "informed consent", but they don't actually

understand what it means, which is to give multiple opportunities for questions and answers and multiple options, including clearly stating that you do have the right to decline.

That is a woman's right. If she chooses to go against medical advice, that is her right. It is her body and it's her baby. Even if the medical professional doesn't agree, they should be protected, but they should also be within their rights to respect that woman's wishes and allow her birth to unfold. If there is an adverse outcome, the person who is most affected by that is the woman. She has to live with that. I think we've had this sort of infantilisation of women, this kind of "we know best" narrative, when actually women do know best about their own body. There are a lot of self-responsible women out there who are doing the research. They are reading all the research papers. They're reading the books. They're doing the prep themselves to understand what it is that they want for their children and their bodies. Being able to be respectful of that is something quite crucial and really simple to do.

The CHAIR: Wonderful. Thank you both for your time today. That takes us to the end of the session. If there were any questions taken on notice, the secretariat will be in contact. Also, if Committee members have any further questions that they come up with after today, the secretariat will be in contact about those as well. Thank you again for your evidence today and for coming in.

(The witnesses withdrew.)

The Committee adjourned at 17:00.