Submission No 929

INQUIRY INTO BIRTH TRAUMA

Organisation: Zamzam Mums and Bubs and The Still Nest

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NSW Parliamentary Inquiry into birth trauma

This is a joint submission by Zamzam Mums and Bubs and The Still Nest.

Introduction

As recognised in the NSW Blueprint for Action – Maternity Care in NSW (March 2023),[1] for most women and their partners, pregnancy, labour and birth and the transition to parenthood are profound life events. Women's experiences during pregnancy and childbirth influences their ability to parent, especially in the early days. Providing socially and culturally respectful maternity care assists with ensuring physical and wellbeing outcomes for the woman, her partner and their baby.

Pregnancy and childbirth are also major life events that place complex demands on women's physical and psychological health and wellbeing.[2] We believe that as a society, we need to see a holistic shift in how we view birth. As a society, birth is pathologized and we see the birthing process as a disease that needs to be medicated. Experiences of birth trauma has far reaching impacts on a woman and her family, including the quality of care received by a child in the critical first 1000 days of life.

Women have a right to a dignified birth and we believe in the utmost importance of gentle and compassionate maternity care with the goal of preserving the dignity and honour of women bringing a life to this world.

[1] https://www.health.nsw.gov.au/kidsfamilies/MCFhealth/professionals/Publications/maternity-care-in-nsw.pdf

[2] Brown SJ, Lumley J. Maternal health after childbirth: results of an Australian population based survey. Br J Obstet Gynaecol. 1998;105(2):156–61.

Fundamentally, we believe in the need for a systemic change needs to occur in the way birth is viewed in Australian hospitals. Birthing women ought to be treated in a respectful and dignified way. Birth is a natural process that should be supported by caring professionals who trust in the mother's ability to birth her child. The act of birthing should not be perceived as a medical condition that needs to be treated and medicalised.

Summary of recommendations

A Parliamentary Inquiry into Birth Trauma is long overdue, and this submission shares the six below recommendations informed by our consultations.

1. Deliver pre-birth education delivered in community settings
2. Fund post-partum support and embed women's health physiotherapy after care within antenatal maternity care
3. Greater access for partners and families to provide postpartum support
4. Implementation of a culturally safe antenatal and maternity care strategy by NSW Health
5. Expanding successful models of care such as publicly funded homebirths and midwifery group practice to ensure continuity of care and positive birthing outcomes
6. Create a culture of systematic reform to address birth trauma – including change of language and rhetoric and proactively support birthing women to provide feedback and complaints about their birthing experiences to create a culture to improve patient safety outcomes

Data collection

As a trusted grassroots initiative, women in the community have been candid in sharing their experiences with ZamZam mums, and many are doing so for the very first time. In response to the Parliamentary Inquiry into Birth Trauma, an online survey was conducted. Thirty one women in based in South Western Sydney, the majority of which identify as being from a Culturally and Linguistically Diverse background have completed as survey to inform this submission. In addition to the surveys conducted, numerous interviews and an online discussion was held to discuss the key themes relevant to birth trauma.

This submission includes extracts of various case studies to inform the Parliamentary Inquiry into Birth trauma.

Formal complaints are generally low

This submission is of particular importance due to an overarching low level of formal complaints made about negative issues they experienced. Only four of the 31 women surveyed lodged a formal complaint. Some of the reasons why women did not lodge complaints include a lack of faith in complaint management systems and are outlined below In the following quotes:

- "At the time of the incident, I wrote out a huge complaint outlining the dates and facts of everything occurring. When it came time to submit I was too scared to as I didn't want there to be repercussions for other vulnerable women. Having given birth again in a different hospital and experienced similar health circumstances but extremely different care I feel so much worse to have left it for so long. It's already a scary time for most women, the unnecessary bullying and force that occurs is shocking. Thank you for inquiring and assisting those of us who don't know what they can do."

- “Despite being a lawyer and assisting others to lodge a complaint about their issues, it felt too overwhelming to take the steps to do this for myself. It has taken me 4.5 years to write down and reflect on the issues I experienced during my birth due to this Inquiry”.

Those who lodged complaints expressed numerous feedback, including denial of their series of events by the Hospital. One participant shared that a complaint she lodged through assistance with a volunteer Zamzam member who was also a member of the local hospital consumer committee led to a positive outcome in her second birth.

About Zamzam Mums and Bubs

Zamzam Mums and Bubs (Zamzam) is a volunteer-run community support group based in South West Sydney. Zamzam started Mums and Bubs sessions in January 2019, going on to develop prenatal health and wellbeing sessions for pregnant women and their partners. Zamzam has an inclusive focus on women from a culturally and linguistically diverse background and incorporates an Islamic faith-based approach to its activities.

Zamzam works with local services and professionals to deliver informative sessions for participants regarding women's health, mental health, birth preparation, parenting as well as other topics addressing maternal health and wellbeing. Zamzam partners with organisations such as Greenacre Area Community Centre, Community Support Services and Tresillian to deliver its programs. Zamzam recognises the need for community programs that are directed at building the capacity and potential of mothers. Zamzam therefore differs from traditional playgroups in that it focuses on meeting the needs of women who are primary carers.

About The Still Nest

The Still Nest is a grassroots social enterprise providing a safe space for bereaved families, and individuals who experience infertility and birth trauma from culturally and linguistically diverse (CALD) communities. Baby loss through miscarriage, stillbirth or infant death increases the risk of depression and anxiety in women. This risk is further exacerbated in bereaved parents from CALD communities, including migrants and refugees. The rate of stillbirth in women from CALD communities is double the national rate. This large disparity is NOT reflected in the number of resources available to women from CALD communities. Unfortunately, support that is culturally responsive is not readily available.

The Still Nest aims to raise awareness of the impact of infertility, birth trauma, and child loss in families from CALD backgrounds. The Still Nest Podcast is the first initiative by The Still Nest, and it shares lived experience of infertility, birth trauma and baby and child loss from diverse communities. The first season focused on the experiences of Australian Muslim families (the first of its kind), and the second season to be released in October, coinciding with International Pregnancy and Infant Loss Awareness Month, incorporates the experiences of the wider community, showcasing the diversity of Australians and their unique nuanced challenges when navigating stillbirth and early pregnancy loss. Host Dr Fatima El-Assaad, an Australian-Lebanese academic and medical researcher, and a bereaved parent, interviews families impacted by infertility, miscarriage, stillbirth, and infant loss. The first season has been downloaded several thousand times.

The Still Nest acknowledges all babies and children lost and their bereaved families.

The experience and prevalence of birth trauma

A significant portion of the interviewees shared their experiences of trauma which includes:

- lack of pain management
- lack of informed consent
- lack of timely care
- poor quality of after-care and follow up of birth injuries
- lack of cultural safety and cultural competence

A number of survey respondents shared that their requests for pain relief measures, such as epidural and access to a bath were not provided.

Mother J, August 2018
The pain management I requested was not prompt, and there was a delay in receiving medication. Once pain set in after a C-Section and I buzzed for it, it was then also delayed for up to an hour. I had this experience twice at the same hospital. For the first few days only my C-section stitches were checked until I asked about the vaginal stitches being checked.
Spinal block did not work properly and only worked down half my body, anesthetiser didn't believe and when she did a pain test and I told her what I felt, she looked up to check if I could see in the above mirror before giving me additional anaesthetic.
I was very anxious prior to the scheduled c section and requested to be put under general anaesthesia but they declined because I had already had 2 C-sections before. I ended up having some sort of seizure/panic attack in there.

Water births

Some of the issues raised affecting informed consent and exercise of choice include the limits to the ability to have a water birth. Water is a simple, effective and readily available and has many potential benefits in labour and during the birth. During labour and birth, the benefits of water can include increased comfort and mobility, a deeper sense of relaxation, increased capacity to tolerate pain and improved blood flow to the baby.

Below are a number of experiences about this:

- *"I wanted to try water birth or at least sit in a bath during labor. I was not allowed to as they already popped my waters without telling me and then started the induction drip and baby's heartbeat needed to be monitored so I missed out on that. I also was not allowed out of the bed to get some relief in different positions as the heart rate monitoring kept playing up every time I got out of the bed trying to get in a position that gave me relief as I wanted to give birth without pain relief."*
- *"I wanted to stay longer in the bath, however the midwives didn't allow me, saying it slowed down labour."*
- *"I asked for water birth but they were busy."*

Mother Y, March 2019

“I was not advised that there would be limitations placed on my ability to birth in a bath due to my gestational diabetes, and assumed it would be an option I can use. When my contractions intensified almost 24 hours into my labour, I expressed to the midwife that I was now ready to head into the bath. I was told that this was not an option due to my gestational diabetes and the baby needing to be monitored. I regretted not taking a more active role to advocate for myself. Despite being a trained lawyer, I was unaware about hospital and birthing processes and felt that my ability to make an informed choice was somewhat limited by not being advised about all of my options. Not long after this, I felt that I could no longer bear the contractions and requested the epidural.

I had come to hospital with my bathing suit which was damp from a relaxed swim at Mcivers women's bath just hours before my early labour pains started. The significance of this space is not lost on me - prior to colonisation, this site had long been a bathing area and birthing place for women of the local Aboriginal people. To me, it remains a reminder of the need to connect with traditional spaces of birthing and the lost opportunities I had to have a water birth. Swimming played such an important role throughout my pregnancy, and I swam most days during my last trimester during a record heat summer. I believe that if I had the opportunity to have a water birth, I may not have needed the interventions and would have had a more positive birth. I was also able to withhold use of epidural for an extended period by using the shower frequently. I have frequently ruminated about how my birth could have been more positive given the issues I faced.

I would later learn some of the challenges from the vacuum delivery, including prolapse which I suffered and was able to treat with support from a private physiotherapist. I feel that the public maternity system should continue to provide support to women suffering post-birth injuries.

At the maternity ward, the nurses advised me to wake up my son more often for feeds since I had gestational diabetes. However, I experienced issues with breastfeeding and was also told that my baby was sleepy. On my first night, a midwife asked me "sweety, are you on methadone". Upon replying that I wasn't, she told me that the epidural can have an impact on making my baby feel sleepy.

This made me feel guilty of my decision to seek pain relief, and over the year of seeking to recover from my prolapse, I spiralled into a guilt cycle about the impact of the decision to use epidural and the impact of the vacuum on my prolapse. Prolapse was a distressing process for me as it prevented me from returning to exercise sooner and exacerbated my emotional eating, leading me to gain weight post-birth. I will always be left to wonder if a water birth could have been the integral change in these experiences.”

Mother S, February 2020

When I arrived at hospital, the midwife on duty rolled her eyes at me and asked “why are you screaming?!”. She proceeded to ask her secondary nurse to check how dilated I was. No one mentioned the use of hands. I’d never been checked so had no idea what this entailed. The force of her fingers suddenly inside me shocked me and took my breath away. The main midwife then asked the secondary “did you sweep her?” To which she said “oh shit I forgot!” And SHOVED her hands back inside me once again without my consent. She then said “you’re only 2cm you’re not even in labour yet! Why are you even crying!” The next 28 hours with her over two shifts were horrifying. She was almost cruel on purpose. She continually “sweeped” me and told me after the fact “I just sweeped you so let’s see how you go now”. She barged in at one point and said “I’m breaking your waters now.” I said no. Pleaded for her to wait a little longer. My husband yelled at her to leave me alone and I cried and told him to not fight with her because she was in charge and was clearly on some evil power trip. She constantly mocked, scoffed and was just so unsympathetic and kind. She fought back saying “I have been on night shifts here for 27years (maybe 17 can’t remember) and I’m telling you you’re waiting for nothing. What are you waiting for? You’ve been at 5cm for 15 hours. I’m breaking your waters.”

We complained to another nurse about her. Moments later the main horrible midwife came in and told us we would be ONLY taken care of by her from now on and that we wouldn't be seeing the other nurse we complained to again. A few more hours passed. She came in and I cried to her about my back pain. That I couldn't lay on it any longer. I was in agony I asked if there was another position to help progress labour and alleviate my pain. I said I had heard about midwives helping with positions and what not even with epidural. She said no and that all she could do was incline the bed "to let gravity help". She inclined the bed so much that for the next few hours I clung to the side rails so as to not fall off. I was too afraid to say anything even though my arms were exhausted and back was still in agony because I thought it was helping baby progress. A few more hours and she came in and said "ok are you wearing any jewellery?" I said no. She said well I've just spoken to the doctor and it's time for a c section. I broke down. I pleaded. She said no things aren't progressing and again wondered what I was waiting for and said "this baby ain't comin'". I was wheeled into a c section 20 mins later. It was horrible.

I couldn't stop shaking during the procedure and 'felt' every shove and tug. They wouldn't let me have water afterwards. I was dehydrated. They had misunderstood the doctor who said no solid food, not no water. When he came to see me I begged for water and he yelled at them to give me some water. I was in hospital for 5 days and they never washed my son for 3 days even though we asked they kept saying "next shift the nurses will". My son was covered in surgical blood and guts and stunk. So my mother in law finally washed him when we realised they were ever going to. They never showed me how to breastfeed, swaddle, bathe. NOTHING. My son couldn't latch and lost so much weight and was jaundiced they just said my nipples were too large for his mouth. When we got out I was a butchered woman….the shell of the woman I walked in as. I walked in young and strong and healthy. I walked out a mutilated and mentally destroyed version of myself. My sons feeding never improved and he eventually fell off the growth curve. I tested positive for depression at my postnatal appointments but I only had one conversation with a counsellor through trisillian and that was that.

It was horrible and it took me 3 years to even want another child as I've always wanted a sibling for my son. I did it but am still so heavily scarred that I will never have any more kids again even though before my birthing experience I thought I would have 3-5 kids.

Mother A, July 2018

I had 3 midwives in my room. One of them checked me and said I had dilated 9cm. She said that I'm very close to giving birth. She said if I stand up, it will help me to give birth quicker. So they made me stand up. I was in agony, didn't feel like I was in control at all. My husband was supporting me while I was standing. *All of a sudden all of the 3 midwives were gone out of the room. At the same time I had a big contraction and an urge to push. So I pushed and I ended up giving birth, my daughter was born and hit the ground head first.* My husband was in shock with what he had witnessed, he was yelling for the midwives to come back to the room. I was trying to process what had just happened, wanting to experience the relief of birthing yet unable to. It's been a little over 5 years since this experience, it still feels like yesterday and I get a knot in my throat just recalling it. I was experiencing anxiety for a long time worrying about my daughter's health, wondering if the birth caused any issues.

Mother K, February 2019

My OB wasn't concerned or supportive when a nurse called him back to the hospital to check on me after a liter plus hemorrhage. My baby was in special care and I hadn't met him 3 hours post birth. He said "she's fine, leave her alone" I was in total shock. A nurse then painfully hand pumped my breasts (incorrectly I later discovered) and when I said no she told me to "think of the baby". Another nurse said "we didn't think he'd survive" about my baby.

Where do I begin. I feel that many of the medical ‘professionals’ are not trained in understanding the physiological and psychological needs of a birthing woman. In hindsight, I feel that so many things that happened during my labour and birth could have been prevented had I been given the correct support and guidance.

So much early intervention led me to the operating theatre for an emergency forceps delivery and to this day I am still recovering from the trauma that has imparted on me. The constant changeover of shifts from one midwife to another and each having very different approaches left me feeling very anxious. The last midwife ultimately decided that I had had ‘enough’ and that things were not progressing after laying me flat on my back and instructing me to push for an hour even though my body didn’t have the urge to. It all went downhill from there once she said I didn’t have the energy to keep going and that it would be better if I received an epidural so that I could ‘rest.’ Now that I look back, I feel like it was more so that they could get things rolling and get you out of there as quick as possible. I feel like birthing women are viewed as a nuisance and as just another number on the system.

Feeling very vulnerable as a first time mother, I agreed to everything, even though I was hesitant every step of the way. They (doctors and midwives) really make you feel like they know better and word things in a way that makes you lose all hope. Especially when it comes to the baby’s health and ‘chances of stillbirth increasing’ if they let the labour go on for too long. After receiving the epidural, things just got worse from there. They said that the baby’s head was ‘stuck’ and even though so many different nurses (both male and female) kept trying to manually reposition the baby's head nothing was working. At this stage I was shattered as I had never felt so exposed and vulnerable in all of my life. It eventually led to a forceps delivery and third degree tears which took a good 6 months to somewhat heal and for me to feel some type of ‘normal’.

The aftercare was also just as horrendous. No proper advice was given to me on what I was to expect once I left hospital. No proper guidance on breastfeeding or how to care for my emotional and physical wounds as a first time mother. Especially considering what I had went through. Their main goal was just to try to get me out of there as quickly as possible to bring the next patient in. Once I went home everything spiralled even more from there.

I couldn’t sit properly for more than a month due to the pain from the stitches. I ended up getting mastitis four times within the first two months of my baby’s life. This led me to fall into a deep pit of depression. I felt so hopeless and so useless that my body was betraying me like this. I also felt like I couldn’t bond with my baby properly because I was just occupied with trying to make myself feel better physically. *I had absolutely no knowledge about lactation consultancy and just fumbled my way through the dark and educated myself on breastfeeding by doing hours of research and trying to care for a very unsettled newborn at the same time.* There were so many different voices coming from everywhere. One advising to stop breastfeeding altogether, one advising to pump, another advising to top with formula. Everything was just too much.

I pray that no one has to go through what I went through, especially as a first time mum. What they do to women in hospitals is absolutely horrendous.

Cultural Safety and competency is essential to address birth trauma

For many Muslim women, observing modesty is a key element of cultural practice and a significant portion will have preferences to interact with a female healthcare team. The extent to which hospitals have accommodated to this varies based on the survey responses and interviewed. Muslim women commonly observe certain religious practices during their maternity journey to varying degrees. However, for some women having a female healthcare team is not important, as rules around modesty are relaxed in medical settings. What is important to note is ensuring the woman and her preferences are at the centre of the interactions and establishing clear preferences right from the first interaction, and to respect these choices.

While some of the interviewees felt that their cultural needs were respected, in other cases, a request for a female medical professional was not met positively and affected their quality of care. This highlights the need for cultural safety and competency training and for discussions about cultural needs to be discussed comprehensively part of the antenatal care team.

Mother N, July 2021

On my third night in the maternity ward, there was a male nurse on night shift that just walked in without more than a verbal “knock knock” a second before he pulled the curtain to come in. As a woman who wears the Hijab, I’m required to be veiled around most men. When I explained that I needed a minute to put my hijab on he seemed confused. It was clear that he hadn’t had any cultural sensitivity training. I felt uncomfortable that whole night and specifically didn’t ask for help because I didn’t want him to come in to my room.

Mother L, July 2021

I had a number of issues with staff leading up to delivery that ultimately boiled down to a combination of being spoken down to and treated poorly as they believed I was uneducated and oppressed making bad medical decisions and neglecting my unborn child for either asking questions to clarify WHY courses of treatment were being offered, requesting alternatives or declining action plans that had no basis or necessity.

One particular incident began a whole series of appointments where I was treated extremely disrespectfully as I had hurt a doctor's feelings by requesting a female to do an ultrasound and physical check. I was told by them it was okay because there would be a woman nearby or in the room if I wanted and was disregarded when I explained I felt uncomfortable with this being done by a man regardless and then was subjected to a lecture by him about how I was intentionally harming my baby by rejecting his assistance and that it would be my fault when I went home and my baby died meaning I'd have a still birth.

I already had a scheduled appointment with a female for ultrasound and check-up the following day so opted to leave. Every appointment after that I had to sit as they read his case notes and listen to the "poor Dr’s" comments. I was told I didn’t know what I was talking about when I said I didn’t appreciate being treated poorly or spoken to in such a manner and dismissed when I raised a complaint about his still birth comment. I found myself having to prove I wasn’t uneducated constantly and that I wasn’t being forced into anything by my husband because they couldn’t comprehend I was capable of seeking information regarding my care myself.

I would overhear the midwives talking about my case in the hallways to the point where a doctor had to go and tell them everyone could hear them and they were breaching confidentiality. I was fortunate to receive care towards the end by the midwife I had had at the appointment with the male doctor who sat with me and asked what had happened because she was confused how things had escalated to that point. I then had my next appointment with the head doctor who ensured that my delivery went smoothly.

Overall, I was subjected to condescension, neglect, poor treatment, gossip and abuse from medical staff who wanted to defend the ego of a doctor who felt like my request for a female in a very commonly understood sensitive area of care was a hit against his ability to do his job. Even as a typically strong and opinionated person capable of standing up for myself I was reduced to tears at a number of occasions when I was yelled at or even called up to tell me how incompetent I was.

I attempted to change hospitals but was unable to do so due to covid restrictions and the late term of my pregnancy. I contemplated travelling a few hours away in order to go into labour completely out of area but due to the onset of lockdown was unable to do so. Prior to these issues (starting around 36 - 37 weeks and then having multiple appointments a week until delivery at 40+3) I had had very little appointments and there was talk of some things falling through the cracks (e.g. iron infusion not being completed as doctor who called felt it wasn't necessary but shock at my next appointment when it had been left).

Mother J, August 2018

Despite giving birth in a private hospital, my birth experience was not culturally respectful or accommodating. I requested that my curtain stay closed and any males please notify me before entering. All male staff entered without any announcement including meal servers, cleaning staff and male paediatrician. At times I would wake up and find them in my room when I wasn't adequately dressed.

Also, male partners of birthing women had access to the shared room where the midwife would support and teach the new mum's how to breastfeed. I felt uncomfortable and struggled silently in my room. When I said something to object, they said I could sit on the side and turn my back. Being a woman that wears Hijab I struggled to manage covering myself sufficiently while having my breast out and baby was unable to latch while the males were in the same room.

Straight after Caesarean obstetrician left the room, husband was given the baby and I was left with the nurses. During this time the men that transport patients came in (before I was covered up) and the Middle aged man stood by the operating table staring at my uncovered private parts. I was struggling to breathe and couldn't bring anyone's attention to what he was doing. He then rolled my body onto him my face and chest touching his stomach (which didn't happen with my other two c-sections at another Public hospital). I struggled for years to deal with that violated feeling. Even until this day I feel so disgusting and enraged when I remember what was allowed to happen to me when in such a vulnerable position.

Disproportional impact of COVID-19 restrictions on birthing women based in Western Sydney

The disparate impact of the COVID-19 pandemic for Western Sydney communities has pointed to health disparities, including the longstanding inequities in maternal and infant health. Through harsher restrictions seen in Western Sydney Local Health District and South Western Sydney Local Health District, the wellbeing of birthing women was placed at risk with long-lasting side effects of separation from support during this crucial time of their lives.

A directive on visitors was issued by the Western Sydney Local Health Distrcit (WSLHD) a week after Greater Sydney entered lockdown and COVID-19 cases began appearing in

Sydney's west. Visitors, including partners visiting newborn babies, were banned from wards across the Western Sydney hospitals.

Kristyn Begnell was working as a consumer representative at the Western Sydney Local Health District (WSLHD). She claims that after she spoke publicly last month about the WSLHD's "rogue" decision to ban partners from maternity wards at Blacktown, Westmead and Auburn hospitals, she was sacked.

"Every day I was hearing a new story of fathers being sent home right after the birth and the mother's distress and it got worse and worse," Ms Begnell said.[3]

Mother N, July 2021

"It was lonely and isolating, those early days are unfortunately tainted with sad memories of not having any physical contact with my husband or family. I did not have any home visits from my midwife and my 6 week check at the GP was awful and undertaken in the car park with makeshift walls."

Mother L, July 2021

"Lockdown had just begun a few days prior so my husband was unable to attend and support me in appointments after I had experienced horrible treatment and then was also limited in how long he could stay with me for induction and after birth. After experiencing a lot of stress surrounding my hospital visits it was frustrating that when we made the effort to plan so he could be there as an extra advocate he was asked to leave the area due to covid restrictions."

Maternity models of care conductive to positive birthing experiences

Numerous women interviewed and surveyed shared their positive home birthing experiences after a traumatic first birth. One mother shared the below statement:

"Looking back, especially after having two incredible subsequent home births, how different things would have been if I was in charge of my body and if I was given the space and time to follow my intuition".

Midwifery Group Practice

Midwifery Group Practice is a model of care which consistently receives a high level of positive feedback. However, the availability of such services are limited. Midwifery Group Practice (MGP) enables women to be cared for by the same midwife (primary midwife) supported by a small group of midwives throughout their pregnancy, during childbirth and in the early weeks at home with a new baby. In doing so, MGP provides continuity of care.

Midwifery care focuses on women's individual needs or 'woman-centred care'. Evidence shows that a women who receives care from a known midwife is more likely to have a normal birth of a healthy baby at term, have a more positive experience of labour and birth, be more satisfied with her care, and successfully breastfeed. Where situations arise that indicate a

[3] Woman who spoke out about "rogue" COVID policy in Sydney hospitals sacked. (2021, August 3). *ABC News*. https://www.abc.net.au/news/2021-08-03/western-sydney-health-staff-sacked-for-raising-concerns/100344948

need for medical involvement, midwives work collaboratively with medical colleagues to coordinate the best care for mother and baby. The private midwife will continue to provide care regardless of the need for medical involvement.

Mother N, July 2021

*"*I had a very positive birth experience and I give a lot of credit to my amazing midwife and the midwifery group practice (MGP) program I was in. She heard and respected what I wanted and did not want to happen during my pregnancy, labour and birth. She advocated for me and always asked for my consent*".*

Mother R, July 2020

*"*My birth itself was a positive experience ONLY because I was selected to be part of the Group Midwifery Practise. Had I not been selected I would have had a VERY different birth. My birth was long and hard. I had a posterior baby and laboured for a total of 5 days. I know for certain that if my midwife didn't advocate for me in those 5 days I would have been forced and coerced into inductions and the like. I'm grateful for MGP and it must be an option for birthing women in all hospitals across Australia*."*

Mother RS, February 2021

"When I was pregnant with my second, I was reluctant to go back to the same hospital as I didn't feel safe after my experience with my first. However after making the complaint, I was offered the Maternity Group Care (MGP) program and reassured I would be taken care of in the process. It was such a great experience from the very first appointment up until discharge I was treated so well and felt so comfortable. The team were so great and knew me by name!"

Publicly funded homebirths

The growing body of research into homebirth highlights the many advantages of having a baby at home for low risk pregnancies. The strong demand by midwives and pregnant women for access to homebirth led to the publicly funded homebirth program, which is available for a small number of women. For a select number of women in NSW, including Royal Hospital for Women and Royal Hospital for Women, home births are publicly funded and free. However, for many women in South Western Sydney, such accessibility is limited and the costs are a significant deterrent.

Mother S, March 2022

As it was my first time being pregnant, I had always planned to give birth in the hospital and to go through that system. However, I got pregnant during the COVID-19 pandemic and I remember reading news articles from trusted sources about horrible birthing experiences due to covid restrictions. I also didn't want only one support person by my side while in active labour then have them kicked out of the hospital leaving me alone with a newborn. I also had hyperemesis gravidarum and I didn't want to travel to the hospital for every check up.

Additionally, my sister had a successful homebirth which also encouraged me. So I decided to have a home birth myself. I went to my GP for my initial check, he gave me a referral letter for my selected private midwife and for my local hospital. I also hired a doula who provides a hypnobirthing course. This course was absolutely essential for me to learn about the physiology of birth, the medical options available to me, it helped me navigate my personal anxieties about birth, it informed me on the history of birth, and taught me physical and mental strategies to manage the pain associated with labour.

My private midwife was amazing and she provided prenatal and postnatal care in my own home. Over the course of months before I gave birth, I was very comfortable with her and trusted her. She wrote out scripts for all my ultrasounds and tests and explained to me exactly what was going on and why. I also made a visit to the hospital in my local area to establish myself as a potential patient. When I told the midwives there that I was planning on having a homebirth they were all supportive and excited for

me. I absolutely wanted to ensure the safety of my child and myself before going ahead with a homebirth, and my ultrasounds and checks found no abnormalities that would warrant medical interventions. So the day of the birth came and I felt as prepared as I could possibly be. I had a great team of supportive people that I trusted and felt safe around from my midwife and doula, to my husband, my mother, and my sister. I started feeling my first contractions around 2am on Friday.

My doula came to my house around 8am. My midwife also came early around 7:30am and - with my consent - she checked how dilated I was, and then left to check on other patients. I was about 2.5cm. My labour progressed and I used the shower and pressure points as pain relief, with my doula present the whole time. I was moving and walking around as I wanted to. My water broke around 12:30pm, and we had filled up the inflatable birthing pool with warm water. I entered the pool and immediately felt relief. It was remarkable just how much relief the warm water and floating sensation provided me. As I was progressing, we called my midwife again and she made her way over. I held my husband's hand and focused completely on my affirmations and the mental preparation that my hypnobirthing course had given me. I felt very safe and supported. I also felt like my body knew what it was doing. I pulled deep into my spirituality (which is important to me as a Muslim woman) and I finally "let go, and let God." My daughter was born at 2:55pm on the same Friday that my contractions started, 3770 grams, perfectly healthy. I had minimal tearing that didn't require stitches. And after getting out of the pool with my daughter in my arms, I laid on the couch and my daughter was on my chest, still connected via the umbilical cord to my placenta. She immediately started rooting around looking for a breast to latch onto and she did, successfully.

We allowed the umbilical cord to turn white before cutting it, and I birthed my placenta naturally shortly after. I then made my way into my own bed and it was the most amazing thing to have all my loved ones next to me, supporting me and my newborn baby. I wasn't alone in a cold, scary, and unfamiliar hospital environment. My midwife stayed for many hours after my birth to ensure myself and my baby were okay, and she visited us every day for the next three days, then weekly. I can't overstate just how grateful I am to have had such a positive birth experience. I believe ALL women deserve empowering and supportive birth experiences - especially if they choose to birth in hospitals. Birth is something that every single human on this planet has to go through to be here. Providing empathetic, un-rushed, and supportive care to birthing women should be our country's top priority. We should invest in learning more about healthy un-medicated physiological birth, and the potential benefits of it.

Need for appropriate and adequate post-partum care

The majority of women interviewed shared that while they were satisfied with the attention they received during birth, they did not see the same level of after-care provided.

Mother R, 30

"*My issues with my birthing process was postpartum. It was incredibly rough, I had lots of breastfeeding issues which weren't addressed in hospital. I raised my concerns and asked for help. They responded with forcing me to stay longer than expected in hospital to get better at breastfeeding but offered no help or lactation support. Moreover, I had a really tough time adjusting to motherhood. At my final postpartum visit from my MGP midwife, she flagged a social worker to contact me from the hospital as she suspected I may have postpartum depression. I didn't receive a call until 6 months postpartum. I had to battle my depression and anxiety on my own in the midst of Covi*d."

Lack of opportunities for informed choices

The prevalence of birth trauma amongst women can be traced to myriad issues, however a key issue is the link between a lack of knowledge about birth itself, birth interventions and their purpose, nature and consequences and birth trauma.

Birth education is important because women have a right to a dignified birth. When a doctor or midwife exploits their position of authority and expertise to force birthing women into interventions that they do not fully understand the nature and repercussions of, or cannot give their full consent to because they are birthing, this is an abuse of trust and care. It harms the doctor/patient relationship and results in possible lifelong mistrust of the hospital system and doctors.

A number of the women who were interviewed who took additional steps outside of the hospital context to improve their birth education literacy such as enrolling in hypnobirthing courses, attending externally provided information sessions by doulas and midwives. They informed themselves about the physiological nature and stages of birth and the interventions a hospital may want to perform during the course of birth. This resulted in positive birth outcomes as mothers acted on their knowledge and most importantly, recognised their own agency and right to choice in their own births.

From a home birthing mother: "*I also hired a doula who provides a hypnobirthing course. This course was absolutely essential for me to learn about the physiology of birth, the medical options available to me, it helped me navigate my personal anxieties about birth, it informed me on the history of birth, and taught me physical and mental strategies to manage the pain associated with labour…Birth is something that every single human on this planet has to go through to be here. Providing empathetic, un-rushed, and supportive care to birthing women should be our country's top priority. We should invest in learning more about healthy un-medicated physiological birth, and the potential benefits of it*."

And from a mother who experienced trauma: "System needs to change to provide better physiological birth preparation for women at risk of tears."

Mother Y, March 2019

I would have liked to have an opportunity to be given information from the midwives and gynaecologists I saw to provide me with comprehensive medical advice. I did not have the headspace during my pregnancy to undertake further research into birth interventions, nor did I seek to make a birth plan because I had faith in the medical professionals to advice me of my options to make an informed decision.

Mother A, May 2023

My labour and delivery experience was positive due to the information and knowledge I had equipped myself with prior to entering the system. The hospital staff did not provide any detailed information about the induction itself or the vaginal examination to break my waters prior to the induction. There was also mixed information with senior midwifery staff the day prior informing me I could use the birth pool, which the hospital midwife informed me I would not be allowed to do so on the day of. Hospital midwife also interrupted my labour with questioning why I didn't want nausea medication during my labour, telling me to get out of the shower as CTG monitor was having issues and asking me if they can conduct vaginal examination during transition as they needed to see what stage of labour I was at. However, they understood I would not give consent and I was aware of my rights and made their frustrations evident with sighing and walking away.

Mother L, July 2021

There was also a lot of pressure to induce beginning at 36 weeks and when I asked for reasons I was told it was to prevent them being liable for a preventable still birth. I asked for risks to the baby of inducing opposed to waiting it out as the baby was small and wasn't given any information (I have since learnt the benefits of this vs the risks as my next child was born in a different hospital and the staff were fantastic and provided all information and an abundance of support), I was only told time and again that I would be the cause of harm to my baby with eye rolls and "professionals" stalking out then gossiping about me in the hallways. I had to interrupt a doctor at one point to ask of my appointment was done and see if I could leave. I was terrified of what would happen when it came time to give birth there, especially with talk that support people wouldn't be allowed due to covid restrictions."

The trauma of baby loss in CALD communities

Prevention and bereavement care needs to be culturally inclusive, respectful, reflective, and reasoned. The loss of a baby and/or child is significant and devastating for the families involved. Severe psychosocial impact on the families, this is exacerbated by barriers such as finances, language, geographical, accessing online resources, Impact of COVID-19 and access to support, domestic abuse and the mistrust of healthcare and government systems.

There is space to do better to reduce the impact of the trauma of baby and child loss on bereaved families from CALD communities. From our interviews of Australian Muslim CALD women for the first season of The Still Nest Podcast, most guests shared that a person of CALD background did not feel seen or humanised, and they experienced major power imbalances by their healthcare team during and after the loss of their baby.

The key experiences and recommendations shared by our guests are summarised below:

Communication:

- Allow space for the parents to express their preferences – ask, do not assume! Allow parents to express themselves, care may need to be personalized. Also, not assuming mother and father have the same views on terminations and autopsies, even if they both seem to identify with the same faith and culture.
- Sensitive evidence-based communication
- Supporting informed choices
- Improving health literacy pre-conception - active learning from experts, workshops and presentations, information pamphlets and posters, social media sharable videos
- Translating resources to a native language is a good first step, but truly understanding the cultural roots to the subtleties around shame, taboo and secrecy around still birth, miscarriage and neonatal death is important. Cultural competency – is not just language translation! There are many Australian born families that identify with a cultural community who speak English as their first language.
- Acceptable and accessible health information in languages.
- Access to interpreters in birthing suite.

Support:

- Hospital to home – there is no comprehensive local knowledge on culturally-specific funeral services that can be shared with the families. They are often left to support themselves during this time.
- Home to community – there is currently no follow up to both mother and partner/support person after discharge after a loss, very little to no, ethno-religious tailored resources and outreach support.
- For families presenting with a pregnancy after loss – there is no need to retraumatize with the previous story of loss, a centralized history needs to be accessed by all supporting healthcare team.
- Suites dedicated for miscarriage and still born deliveries need to be available in every hospital including the option of accessing a cuddle cot.
- Prevention and bereavement care needs to be culturally inclusive and responsive. Hand and footprints, locks of hair, photographs, dressing baby up, teddy bears, figurines, autopsies may not be appreciated by all families.
- Birthing support partners and family members such as other living children, grandparents and uncles/aunties also need to be considered when providing support.

Shared decision making and power sharing

- Compassionate, personalized, high quality care and support
- Continuity of care and carer, family centred, no re-traumatization of mother, birth history is readily accessible, building trust and rapport with families

Recommendations

Recommendation 1: Deliver pre-birth education delivered in community settings

Knowledge is power, and birth education is a significant factor to influence positive birth outcomes. Expecting women should be taught about the physiological nature of birth, the birth stages and what to expect, pain management (reframed linguistically from “pain” to “surges”), taught natural relief for contractions (such as hypnobirthing, breathing, the connection between tension and longer labour, massage and so on).

Appropriate pre-birth education should be provided at a community setting and grants should be provided to fund these activities to ensure they are delivered sustainably. Pre-birth education should also be delivered more holistically, and it is appropriate to provide education about healthy positive pregnancy and pregnancy outcomes, including pregnancy loss in high school as part of the Personal Development Health & Physical Education Curriculum.

Pregnant women must also be informed about tests taken during pregnancy; interventions offered during birth. They should be thoroughly informed of the purpose, intent, nature, side effects, consequences and necessity to ensure that mothers can consent fully to testing and interventions. Interventions should not be sprung upon a birthing mother who cannot weigh up the consequences whilst she is labouring.

Zamzam Mums and Bubs was set up as a volunteer-led grassroots initiative with the intention to support mothers postpartum. As the sessions proceeded, it was clear to organisers that supporting mothers in the postpartum phase was not enough. Mothers who were attending brought their stories of birth trauma and early postpartum difficulties (such as with breastfeeding, healing from stitches etc) to the sessions and we wanted to help mothers before the trauma was experienced. We saw the importance of empowering women with knowledge about birth to result in better birth outcomes.

A few months into the launch of Zamzam Mums, “I’m Expecting! Let’s Chat…” sessions were started with the intention to educate pregnant women about what to expect in hospital appointments, testing throughout pregnancy, how to support the pelvic floor muscles, birth and breastfeeding. The aim was to inform, educate and support pregnant women to help them achieve the best outcome for birth and postpartum. A core message we wanted to deliver attendees was that having a healthy baby at the end of birth was not the primary goal. The mothers’ experience of birth and her health/physical state had to be a priority as well. A mother whose birth choices were respected, a mother whose dignity was protected should be critical to the birthing experience. To do this, knowledge of the birth process was critical.

To deliver this knowledge, we invited professionals in the field (midwives, doulas, women's health physiotherapists) to highlight to attendees their individual agency, their individual right to choice throughout their pregnancy and in their births, and practical information on how to support a positive birth. Most importantly, it was a safe space for expecting mothers to express their fears, without judgement, and receive support. In the submissions, one mother who attended two of our "I'm Expecting! Let's Chat…" sessions connected with the doula who helped to run the session and had a positive birth experience.

Unfortunately, with a lack of funding and limited capacity of volunteers, Zamzam Mums and Bubs and its "I'm expecting! Let's Chat" programs have been put on hold. With appropriate funding and appropriate resources to recruit a larger team, Zamzam mums could operate to provide mothers with the birth education needed to achieve positive birth outcomes. Community based organisations, like Zamzam mums can take the pressure off public and private hospital systems to conduct birth education and post-partum support that mothers are in dire need of.

Recommendation 2: Fund post-partum support and embed women's health physiotherapy after care within antenatal maternity care

Women's Health Pelvic physiotherapy is an essential allied health service due to the significant changes affecting women's bodies during pregnancy. However, physiotherapy is by and large available to individuals who can afford private physiotherapy expenses. The lack of management of post-partum support can lead to significant long-term issues such as incontinence with significant quality of life repercussions.

We echo calls by the Australian Physiotherapy Association (APA) in 2018 to call for women's health physiotherapists to be included in the care teams for all pregnant women in Australia to reduce the risk of complications and to improve outcomes for women and their babies. In 2019, updated guidelines in the UK recommend the addition of physiotherapists to care teams, particularly for women expecting twins or triplets. This would mean women's health physiotherapists would join obstetricians, midwives, GPs and sonographers in multidisciplinary teams looking after all pregnant women during pregnancy and postnatally.

Currently in Australia, access to obstetric physiotherapy care is available to women in some areas but not in others, meaning many thousands of women every year are missing out on getting individualised care to help support them and their recovery after birth.

- Antenatal care - Prenatal and pregnancy physiotherapist part of antenatal care can relieve pain, build strength, prepare for delivery and aid recovery after your baby is born. In certain countries, physiotherapists are part of the antenatal care team.
- Post-pregnancy Physiotherapy can assess and treat any postnatal pain and demonstrate exercises to improve muscle strength if there is abdominal separation.

Physiotherapists provide customised support to women and in their absence, generic advice about pelvic floor exercises is provided without consideration to common issues such as vaginismus.

Mother N, July 2021
I had some complications with my healing post birth and had to figure it out on my own. There needs to be more subsidised pelvic physiotherapy for every single birthing woman. It shouldn't only be available to those who have the means to pay for it.

Mother Y, March 2019
I suffered prolapse after my birth, with the use of the vacuum being a contributing factor. It influenced me significantly and impaired my post-partum journey, causing me to reduce my physical activity and comfort binge eat. Had it not been for my awareness of women's health physiotherapy and ability to pay for private treatment since pregnancy, I would not have been able to treat the prolapse and would have continued to suffer the negative mental and physical health repercussions.

Mother N, July 2021
There's should be a greater focus on postpartum care. I felt unimportant after giving birth with all the focus being on the wellbeing and development of the baby. After my last virtual appointment with my midwife I felt a huge sense of sadness that these sessions and my ability to reach out to her when I needed were over. It felt like a break up to me and like I was on my own after this point. My recommendation is that there should be continued care or at least a support group in a group setting with a midwife for a year postpartum. Postpartum is not just 6 weeks.

Post-partum support and leave
This should also include lactation support, proper nutrition offered to mothers in hospital, the extension of paid maternal leave to a minimum of 6 months. In fact, Norway has "one of the most generous maternity leave policies in the developed world,"[4] a full year of paid leave for parents to spend with their infant, proving that it is possible to increase paid maternal leave. The midwives sent home program should also be changed to be more supportive, genuine, consistent and informative, rather than a "ticking off the forms" initiative.

Mother N, July 2021
There should be a greater focus on postpartum care. I felt unimportant after giving birth with all the focus being on the wellbeing and development of the baby. After my last virtual appointment with my midwife I felt a huge sense of sadness that these sessions and my ability to reach out to her when I needed were over. It felt like a break up to me and like I was on my own after this point. My recommendation is that there should be continued care or at least a support group in a group setting with a midwife for a year postpartum. Postpartum is not just 6 weeks.

[4] CEHURD. (2012, January 23). *The 10 Best Countries for Maternity Care*. CEHURD. https://www.cehurd.org/the-10-best-countries-for-maternity-care/

Recommendation 3: Greater access for partners and families to provide postpartum support

Support persons in public hospitals should be allowed to stay overnight with birthing mothers to provide appropriate postpartum support. In the absence of this, mothers should be allowed to go home earlier with hospitals sending out midwives to perform the necessary tests there. This will take pressure off midwives working night shifts to support new mothers and their babies. The midwife to mother/baby ratio is dismally low, and much of the postpartum trauma comes from overtired and overstretched midwives working night shifts, unable to provide supportive care.

In light of the negative impact of COVID-19 restrictions had on birthing women in exacerbating the isolation and devastation families experienced after losing their babies, there is a need to reconsider the nature of public health restrictions placed on birth partners and support.

Recommendation 4: Implementation of a culturally safe antenatal and maternity care strategy by NSW Health

To complement the NSW Blueprint for Maternity Care, it is recommended that a strategy is put in place for a culturally safe antenatal and maternity care, reflecting the Federal Department of Health Pregnancy Care Guidelines - Pregnancy care for migrant and refugee women.[5]

It is imperative that culturally appropriate care is provided by maternity services to ensure quality care is provided. There ought to be zero tolerance to systemic and institutionalised racism, microaggressions, missed care and mistreatment. It is evident from the case studies that non-medical factors influence medical decisions. Unconscious bias in healthcare can lead to false assumptions and negative outcomes with significant patient safety and experience ramifications.

Authentic culturally responsive care requires healthcare organisations to do more than provide staff training. To better promote service user and staff satisfaction and wellbeing, organisations need to embed structures to respond to the needs of refugee and migrant communities in the maternal health sector and beyond.

Medical staff need to access mandatory appropriate cultural awareness and anti-racism training at a local level to ensure that they have an understanding of the cultural needs of their local community. There is also a need to have targeted recruitment for bicultural workers and introduce workforce strategies to increase recruitment and retaining culturally and linguistically diverse midwifery, hospital and medical staff.

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[5] Australian Government Department of Health. (2018). *Pregnancy care for migrant and refugee women*. Australian Government Department of Health. https://www.health.gov.au/resources/pregnancy-care-guidelines/part-a-optimising-pregnancy-care/pregnancy-care-for-migrant-and-refugee-women

In our surveys, participants were asked if they experienced racism during their maternity care. A significant portion stated they were unable to verify whether the treatment they received was due to racism. One respondent, who birthed at a hospital in the shared the below quote:

"*I think my OB didn't take me seriously because I looked very different to her usual patients at this hospital. Can't be sure but I definitely did not feel seen by her.*"

Further case studies below demonstrating lack of cultural competency.

Case studies

- "When I first got to the labour room I had the Written Portrait of our Prophet (SAW) [Hilye-i Şerif] in my hand to look at and recite the salawat. I got a massive eye roll from one of the midwives, at the time it made me feel really uncomfortable especially in that vulnerable labouring state".
- "After birth in the ward, one nurse was rude because of the way I had wrapped my baby culturally. She even said "in your culture I've seen your people do this a lot but we don't wrap babies like that here" she was a supervisor"
- "I felt like a lot of the treatment throughout my appointments was made based on an assumption I was not born or raised in Australia because of how I dress. As someone who did not grow up around these areas at all I was especially surprised because I hadn't been spoken to in such a way before and definitely hadn't received so much shock when I'd explain my westernised background despite my appearance. I was also informed by my GP that in these areas a lot of health professionals try to strong arm women as they deal with the same cultural groups over and over but for me it was a definite overstepping of bounds whether I was to their standard or not."
- "Was questioned about domestic violence which is standard protocol but after I stated it doesn't apply to me the midwife went on to add that it's quite common in my culture."

Recommendation 5: Expanding successful models of care such as publicly funded homebirths and midwifery group practice to ensure continuity of care and positive birthing outcomes

The success of Maternity Group Care (MGP) and home births highlights the successful models of care that should be expanded to promote positive birthing experiences and to limit birth trauma. Some of the anecdotal evidence received from midwives consulted points to staffing shortages for MGP midwifery staff. To address this issue, recruitment should be targeted to improve the availability of MGP programs to all birthing women.

Publicly funded homebirths should be available more widely for low-risk births, and it provides opportunities to alleviate demands on staffing. Home birth provides birthing women significant benefits of continuity of care, autonomy over decision making, woman led birthing and an overall positive birthing experience. There is a lack of shame about decisions made and informed decision making is promoted.

Mother R, August 2022

Home birthing was a piece of cake in comparison to birthing in a hospital. I felt safe and wasn't subjected to unwanted vaginal checks. Post birth – I didn't feel rushed to birth my placentae. There wasn't limitations like change of shifts. I wasn't pushed into taking syntocin to birth the placenta and I was given the time of day to do what I needed to do. I had the opportunity to

debrief while sitting on the couch with a cup of tea – you don't get a debrief at hospital. It was such a peaceful and joyous occasion and a non-clinical celebration to experience a peaceful birth. We had several debriefs after the birth and I had lots of opportunities to access support post birth for the next 6 weeks and it was invaluable. The support was available in person and over the phone. I did not have access to this support for my first child. It was chalk and cheese in comparison to my first birth where I did not have access to post-partum support and suffered post-natal depression. The cost is a huge deterrent of $5,500 and unfortunately, we did not have access to this in South Western Sydney.

Below are the quotes recorded by Mother R's midwife who stated "15 years in the system and I rarely heard those words. Homebirth is the absolute best".

Recommendation 6: Create a culture of systematic reform to address birth trauma – including change of language and rhetoric and proactively support birthing women to provide feedback and complaints about their birthing experiences to create a culture to improve patient safety outcomes

As part of the maternity process, all women should access a debrief with a midwife and a consumer representative team member to discuss all aspects of their care. This would support emotional and psychological recovery.

Birthing women should be given comprehensive advice about how to make a complaint and there should be a stronger effort to assist women in making complaints to improve patient safety processes. Assisted patient experience surveys should be carried out by consumer representatives routinely as part of the discharge process. This considers the practical limitations of women having the capacity to engage with the complaint mechanisms while juggling the demands of caring for a newborn and adjusting to post-partum life. Currently, the onus is upon birthing women to engage with the system, and there appears to be a lack of proactivity from hospitals to gather feedback about birthing experiences.

Hospitals should initiate a change in the rhetoric and language used towards birthing mothers. Stop the power dynamics that are asserted by OBGYNs, doctors, anaesthetists and midwives to harass women during birth. Our recommendation is retraining and professional development of birthing staff to be mandatory, taking into account the findings of this inquiry. Birth trauma is too prevalent, the consequences too dire to not push a systemic change which can only happen with re-education of the professionals who are at the root of the trauma.

The submission is endorsed by Mums4refugees Mums4Refugees NSW Incorporated.