

Submission
No 1062

INQUIRY INTO BIRTH TRAUMA

Name: Name suppressed

Date Received: 15 August 2023

Partially
Confidential

Tuesday 15 August, 2023

Attn: Select Committee on Birth Trauma

Dear Select Committee Members,

I write to share my experience as a private citizen and request my name and any identifying information is not published, due to the sensitive nature of this submission. I make this submission relevant to multiple terms of references, however note with disappointment and frustration the exclusion of disability (and therefore experiences of discrimination and ableism) in the terms of reference.

I gave birth in 2020 during the COVID pandemic. I am deaf, I mostly communicate orally through speech and use hearing aids, however cannot hear through face masks. My mother and my partner's mother have died and we have limited social and emotional supports.

I sought care through my hospital's birth center, hoping for minimal interventions and a 'natural' birth. I expressed a keen interest in continuity of care – preferring to be supported by one or a small team of midwives, but was instead seen by different midwives throughout my antenatal period. Due to covid restrictions, my partner could not attend appointments. These factors made it difficult to develop relationships – which I believe is key to minimising birth trauma. Through relationships we are more likely to make informed and supported decisions. Feeling like we can make decisions is key to feeling empowered. Relationships take time to develop. Staff who are overworked are unable to take the time needed to establish solid rapport and trust.

Due to the pandemic and restrictions, antenatal classes were held online, creating both barriers and opportunities for disability access. In my case, I was able to access captions but did miss content and information. This also made it impossible to develop bond with other expectant parents, which might have been a protective factor to support me after the birth.

I had prolonged rupture of membranes and I had a very long latent phase of labour, during which I had painful contractions and was vomiting repeatedly. I was hoping to stay at home as long as possible, but ended up going to the hospital 3 times to seek care before I was admitted. In retrospect I understand now I was seeking a safe and secure environment where I knew I would be allowed to stay until the birth. **I feel strongly that the lack of resourcing and availability of continuity of care and government funded home midwifery for birthing causes birth trauma.** I very much wish I did not make those journeys to the hospital only to be turned away in the dark and cold mid-Winter whilst in pain and vomiting. I exhausted myself and felt pressured by nurses/midwives to make a decision to accept an induction of labour. **Policy changes and additional resourcing of home midwifery and continuity of care is desperately needed to support women to birth at home safely. We also need more funding and resourcing of birth advocates and doulas, available through public systems and offered to multiply marginalised people.**

I was put on fluids and had my baby the next morning with an epidural. I had consented to the epidural to allow me an opportunity to rest after the days of vomiting and pain – I had asked to be supported to kneel to give birth but was told this was unsafe. I have learned this is possible to do safely even with an epidural, with support. I was keen to have some mobility and experience birthing, so the medical team offered to stop the epidural at the latter stages of labour. I did not understand what this would mean, in my exhausted state.

Whilst pushing, my midwife stated that if my child as not born soon, she was going to do an episiotomy – I was stunned by this, but unable to voice resistance in the moment. It felt like a threat. I had read and been told episiotomies were less routinely provided and recent research suggests a natural tear is preferable. This

made me push more than I felt inclined to. My child was born with a second-degree tear, I was stitched for this without pain medication. I do not have memory of whether any pain relief was offered and was in no state to request it. In addition to the long labour, I experienced deaf fatigue from trying to decipher speech by unfamiliar voices – made worse by masks. I was utterly exhausted and unable to advocate for myself, I could not even hold my head upright and due to my position on the bed remember staring at the ceiling without any neck support crying in pain during the suturing. I remember asking the registrar “will you be much longer?” I was unable to express that I was experiencing intense pain and wanted her to stop. I feel it must have been obvious to the young registrar and midwives I was not OK – I saw her look at me with concern, but to my memory - minimal support was offered. These midwives had been with me for hours, so my feeling is, they were likely due to end their shift and complete their notes so their energy and attention was elsewhere.

I believe if I had a midwife with me who knew me and knew how to communicate with me, I might have been treated differently and experienced less birth trauma from this painful experience. I know that my experience could have been much worse.

I was discharged after just one night (willingly). During that night I had a midwife check on me minimally and she expressed relief that I did not need any support as she was clearly overworked, with a huge list of women and babies to support – which she showed me, adding to my belief she had no capacity to support me. I felt I could not ask for help, as she was too busy and other mothers/infants were in more pain or distress. I believed that breastfeeding was establishing well and so did not feel the need to push for her assessment. **Midwives need fairer workloads, to be able to provide decent, proactive (not reactive) care to all birthing families.**

I had home midwifery post-natal visits, and at 5 days old I was told my daughter had apparently lost over 15% of her birth weight. We were admitted to the special care nursery and on admission just a couple of hours later, she somehow weighed at 10% weight loss – I suspect the home midwife incorrectly weighed her using my unstable dining table at home, and have since learned it is also common for babies born to mothers who are given fluids in labour to lose more weight than is typically expected. This would have been reassuring to me at the time, but staff framed her loss as a grave concern, (even though it was not as much loss as initially thought) causing me to feel understandably highly anxious and distressed for her safety and health. I was also unclear about what had actually happened, due to mask wearing and limited efforts to ensure accessibility by staff. **Staff need to be trained to assess for unnecessary intervention – to be able to prevent intervention if it is not needed. Staff need to be trained in d/Deaf and disability access and be proactive in ensuring their communication of information is accessible.**

Lactation consultants at the special care nurse also told me that my daughter had a tongue tie and said the NSW Health clinic to support us with this was closed due to covid, so they printed some private providers we could access ‘if we wanted’. Another lactation consultant and midwives later refuted this – stating she did not actually have a tongue tie and was fine. We followed the initial advice and began a deeply traumatic journey of breastfeeding, pumping and feeding expressed breastmilk via bottles and offering formula ‘top ups’ which meant, even with a supportive partner – I was unable to sleep and relax for more than 30 mins to an hour every couple of hours. I was prescribed a drug to increase breastmilk production – even though it was possible that my milk production was adequate, or establishing. **Continuity of care at this point could have offered me someone I trusted to provide clear advice. This was not offered and I was utterly confused about what was wrong and the best course of action.**

We went home but returned to hospital once again at 2 weeks for more feeding support, on the advice of yet another midwife. At this visit, my daughter was repeatedly shoved violently into my breast by a ‘midwife’ supervising the shift, who was apparently seeking to ‘help’ me with attachment. I was too intimidated to even comment and deeply regret not advocating for my infant and preventing this violence. **Midwives need to be trained to provide safe and gentle care to infants and parents who are experiencing difficulties with feeding. Bullying and violence within midwifery must be addressed.**

We went to the recommended tongue-tie specialist GP and lactation consultant duo and I am horrified I was complicit in the slicing of my infant's tongue frenulum without any analgesia. The memory of this experience causes me flashbacks and anxiety – 3 years later. She bled a huge amount including clots – I could see the midwife/lactation consultant was also shocked by this. I was told to 'press' on her wound regularly to ensure the tongue tie did not return. This pressing on a wound over several days also caused her immense pain and both her, my partner and I deep distress. I profoundly regret putting my child through this experience and have since read various conflicting health articles about tongue ties. I am still unclear as to the evidence base for their 'treatment', whether they actually have a significant impact on feeding, who is best placed to assess that and whether this inherently violent practice was needed. It seems that misogyny is rife within medical research and care – so called best practices for infant and maternal care are often contradictory – how on Earth are isolated, exhausted new parents supposed to make informed decisions when the information is contradictory? **We need more research, evidence and clear guidelines for assessing and responding to infants with tongue ties that may present barriers to breastfeeding.**

Despite conflicting health 'advice' I was able to persist with breastfeeding, and weaned from the pumping and formula top ups. However, at a few months old my daughter, (likely sensing my anxiety from the whole experience of stressed feeding and weight gain concern) began to refuse to feed, either via breast or bottle. I was only able to feed her when she was very tired or 'dream feed' whilst she was asleep. This led to further social isolation as I felt unable to leave the house to make sure she would feed well whilst sleepy, avoiding possible distractions.

Eventually I met a GP with International Board Certification (and IBCLC), she was also trained in the Possums Neuroprotective Developmental Care approach to feeding and sleeping. This GP was a great support and reassured me about our experience and my child's growth. Unlike most IBCLC, because she was a GP, I could see her with bulk billing, making this vital service accessible financially. **I understand there is much industry and therefore profit connected to tongue ties and infant sleep/care, which I believe ought to be more closely monitored and regulated to ensure parents and infants seeking support are not harmed.**

Old fashioned behaviouralist and risk-adverse advice about 'sleep training' prevents parents from safely bed-sharing and co-sleeping which can assist in allowing birthing parents to establish breastfeeding, respond to their child and get adequate sleep. Whilst I did not actually seek her advice, I was told by a midwife at my NSW Health Early Childhood center that I was "making it worse" by responding to my daughter's distress during evenings. This midwife went on to promote sleep training. **Unsolicited advice and blaming parents such as this, undermines a new parent's belief in their decisions, confidence and capacity to parent.** I am aware that some form of this 'sleep training' behaviouralist practice, whether it is 'cry it out', 'controlled crying', or 'responsive settling' is promoted in most NSW Health funded early childhood family care centers/'sleep schools' (Tresillian, Karitane). **I support the Beyond Sleep Training advocacy on ending this: I believe NSW Health should not be promoting such approaches. Education and support to safely co-sleep for those who decide to, should be widely available.** Once I began to safely bed share with my child, both feeding and sleeping eventually became much easier. I made the decision to bed share after discussion with the GP mentioned above and also reading much conflicting information, then following my instinct to be close to my child.

As a deaf woman without access to the NDIS I have no accessible baby monitor, as was unable to source a reasonably priced vibrating monitor. This prevented me from sleeping away from my child, as I was unable to hear and respond to her. A vibrating monitored we purchased from the US arrived and was not in working order – those available in Australia for Deaf parents were several hundreds of dollars which was prohibitively expensive. Co-sleeping allowed me to respond to my child quickly, providing reassurance or a feed, so that we could both quickly get back to sleep.

Supports to allow all d/Deaf and disabled people (not just the 10% who access the NDIS) to parent should be offered or subsidised by government. Barriers to health care for deaf women include NSW Health consistently failing to provide Auslan interpreting for antenatal appointments and even during birthing. It is clear that access to information in a way a person can understand is vital. Whilst this was not my experience,

I urge the committee to consider this – and other intersectional experiences facing d/Deaf and disabled parents and pregnant people.

Australia is a signatory to the United Nations Convention of the Rights of Persons with Disability (UNCRPD), and the Disability Discrimination Act (1992) makes it unlawful to discriminate against disabled people. However, the onus is on the individual to prove and seek resolution of complaints - this is unfair and discrimination is widespread. NSW Health staff need mandatory training in accessibility for d/Deaf and disabled people. Ideally this training should be co-designed or entirely designed and provided by d/Deaf and disabled people. It should also cover and address the pervasive and dehumanising ableism that sits behind much of the discrimination disabled people face. Undoubtedly this is connected to birth trauma for many, especially parents with disability who experience widespread reproductive violence, coercion and removals of children.

Thank you for your consideration of my experience and recommendations. I would be willing to discuss comments made in this submission, I do not wish to give evidence at a hearing.

Sincerely,

References

Possums Neuroprotective Developmental Care: <https://possumsonline.com/research-publications>

Beyond Sleep Training petition with information about issues with behaviouralist approaches to infant sleep, feeding and care : <https://www.change.org/p/families-and-babies-deserve-better-call-for-research-and-options-for-sleep-support-now>

Deaf Australia (2021) Accessible services for Deaf people who use Auslan in hospital and health services: <https://deafaustralia.org.au/wp-content/uploads/2022/09/Accessible-Services-for-Deaf-People-who-use-Auslan-in-the-Hospitals-and-Health-Services.pdf>

United Nations Convention of the Rights of Persons with Disability (UNCRPD): <https://humanrights.gov.au/our-work/disability-rights/united-nations-convention-rights-persons-disabilities-uncrpd>

Disability Discrimination Act (1992) <https://www.legislation.gov.au/Details/C2018C00125>

Women with Disabilities Australia (2009) Parenting issues for women with disabilities in Australia <https://wwda.org.au/wp-content/uploads/2009/08/parentingpolicypaper09.pdf>

Disability Royal Commission (2023), Parents with disability and their experiences of child protection systems: <https://disability.royalcommission.gov.au/system/files/2023-07/Research%20Report%20-%20Parents%20with%20disability%20and%20their%20experiences%20of%20child%20protection%20systems.pdf>