Better Births Illawarra - Answers to Supplementary questions and Questions on Notice. NSW Parliamentary Inquiry into Birth Trauma.

Responses to the Supplementary Questions

Regarding the term "birth trauma":
a. what is Better Births Illawarra's preferred definition of the term? b. why is this the preferred definition?
Our organisation defines birth trauma as a combination of the following two definitions: that it *"lies in the eye of the beholder"* (Beck,2004). Beck's definition highlights the subjective nature of birth trauma and they also conclude that what may be traumatic to a woman could be routine to a clinician. The birth was her experience therefore she is the only one who can define it.
The inclusive definition developed (Leinweb et al, 2022) *"A traumatic childbirth experience refers to a woman's experience of interactions and/or events directly related to childbirth that caused overwhelming distressing emotions and reactions; leading to short and/ or long-term negative impacts on a woman's health and wellbeing."* The second definition is highly valued because 1) it was developed in consultation with professionals and consumer groups. By including consumers in developing the definition, it assists consumers to validate the traumatic experience. This definition also *"acknowledges that harmful interactions by healthcare providers and obstetric violence can traumatize individuals during childbirth."*

2. Regarding the term "obstetric violence":
a. what is Better Births Illawarra preferred definition of the term? b. why is this the preferred definition?
Our organisation recognises that obstetric violence is a form of gendered violence that happens in Obstetric setting, not just by obstetricians which we understand is a common misconception. Better Births Illawarra preferred definition of the term is in line with the internationally recognised definition of the World Health Organisation:
"outright physical abuse, profound humiliation and verbal abuse, coercive or unconsented medical procedures (including sterilization), lack of confidentiality, failure to get fully informed consent, refusal to give pain medication, gross violations of privacy, refusal of admission to health facilities, neglecting women during childbirth to suffer life-threatening, avoidable complications"

3. Can you explain why "informed consent" is necessary for women with respect to decisions they make regarding all aspects of their pregnancy?
The right to informed consent is based on the fundamental human rights to bodily autonomy and bodily integrity. The Convention (women and health), the Committee on the Elimination of Discrimination Against Women (CEDAW) states:
"Acceptable services are those that are delivered in a way that ensures that a woman gives her fully informed consent, respects her dignity, guarantees her confidentiality and is sensitive to her needs and perspectives."

We hear from women in the community and in reading many of the submissions to this Inquiry that informed consent is routinely not being obtained in NSW Public hospitals for routine or minor procedures; women are signing consent forms for Caesarian Sections without fully knowing the risks and consequences of this major procedure and pregnant women do not have the right to refuse treatment. This is contravening the human rights of the woman as her bodily autonomy and bodily integrity are grossly compromised.

The establishment in 2010 of the National Safety and Quality in Healthcare Standards was in recognition of the need to improve the safety and quality of care, including the gaps in informed consent. Women have the right to ask questions of healthcare providers to ensure that high-cost, high-intervention services are not the first option, and that all options are offered and considered in an unbiased, objective manner. The Choosing Wisely initiative and the joint initiative Question Builder by the Commission on Safety and Quality Health Care and Health Direct are tools to assist in informed consent. However demographics such as refugees, culturally and linguistically diverse migrants and First Nations peoples face barriers to asking questions due to power imbalances, cultural norms and the impacts of colonisation.

System and policy literacy also impacts informed consent. It is common to hear that a woman is "not allowed to" make certain choices and that they must "follow X policy". Policies are not legally binding. Policies are often not adhered to by clinicians. For example: A woman making an informed choice about using water immersion to manage pain may be told that her BMI is "too high" or she has been in labour "too long" to enter the hospital or birth centre birthing pool. Neither of these reasons are based on any research. Similarly, the Perineal Bundle that was rolled out across NSW and has since been found to be lacking in evidence. Yet it is being used as a "policy" and is "evidence-based". The decision in maternity care is ultimately the woman's responsibility if she is to maintain her bodily autonomy and bodily integrity.

Responses to the Transcript

(1) *We know the World Health Organization has a paper and—I can also send this through—that most birth trauma happens 15 minutes before the baby is born.*

RESPONSE:

This question was in the context of whether MAPS was a solution to birth trauma. In our response we made it clear that there was no evidence to suggest that having one or more midwives to support a person in antenatal and postnatal care was going to reduce the risk or rate of birth trauma. MAPS being a "better than nothing" solution. What MAPS does not do is address the trauma that occurs in the birth unit during labour and birth itself. We also stated that MAPS was a workforce solution, not a solution to birth trauma. Again, this model is not in line with women-centred care, it is centering the needs of the healthcare system.

Midwifery-led continuity of carer models need to be funded and recruited for. The myth that most midwives do not want to work in these models needs to be dispelled. MAPS is upholding the fragmented system that is a systemic cause of avoidable birth trauma.

We also ask the committee to review the use of the term "Continuity of care". We believe it is being referenced in inaccurate ways. Continuity of Care includes intrapartum care i.e. at birth. Therefore, GP Shared Care is not continuity of care as they do not have admitting rights into the hospital unless

they are a GP Obstetrician. Continuity of Care by an Obstetrician unrealistically and rarely occurs in the public healthcare system.
***We ask the Select Committee to please define what continuity of care is.
***We ask that the Select Committee review the submissions for how many instances of trauma happen in the birth unit not in antenatal and postnatal care.

(2) *Interestingly, I think it was earlier*

this year, or maybe even a couple of months ago—and I can send this through as well—in the UK they've gotten rid of the term "high risk".

RESPONSE

- Six pregnancy terms you probably won't hear again, including 'high risk' and 'failed' (theconversation.com)
- Re"Birth Report Summary. re_birth_summary_.pdf (rcm.org.uk)

(3) *The Hon. NATASHA MACLAREN-JONES: That's fine. I can ask when they come next. In relation to your submission where you talk about a trial that was done—it was in relation to budget and costings—I was wondering if you had any more information? I'm happy for you to take it on notice. You were saying it was one of the barriers as to why they couldn't expand. I was wondering if you had that?*

ALYSSA BOOTH: The M@NGO trial?
The Hon. NATASHA MACLAREN-JONES: Yes. I'm happy for you to take that on notice.
SHARON SETTECASSE: Thank you. Let's do that

RESPONSE

The M@NGO Trial A randomised controlled trial of caseload midwifery care: M@NGO (Midwives @ New Group practice Options). Models of midwifery have proliferated in an attempt to offer women less fragmented hospital care. Caseload midwives manage the care of approximately 35-40 a year within a small Midwifery Group Practice. The trial compares the outcomes and costs of caseload midwifery care compared to standard or routine hospital care through a randomised controlled trial.
A randomised controlled trial of caseload midwifery care: M@NGO (Midwives @ New Group practice Options) | BMC Pregnancy and Childbirth | Full Text (biomedcentral.com)
What is clear is that midwifery-led continuity of care is cheaper than the current fragmented care. To enable this model of care to be rolled out across the remaining nine Local Health Districts where it currently is not offered, we suggest contacting Alison Cummins at
who co-authored the Report commissioned by the ISHLD on making MGP a sustainable model. She is also the lead researcher undertaking research commissioned by the MoH on the MAPS model. She may be a key person to present at one of the next hearings because of her expert knowledge on maternity care models + workforce.

(4) *And the third thing that I would say is, in the same way that Queensland has legislated informed consent, we need to do that in New South Wales because informed consent is not happening. No means no, and even if someone doesn't know all of the policies, if she says no*

or if they say no and you've got a different opinion because you're a clinician, it actually—they are a grown adult. They've just grown a baby. That's okay for them to say no. We all want a healthy baby when we come out. That is the baseline. That's the benchmark. It's actually a little bit insulting to say to a woman, "We just want you to have a healthy baby", because—guess what—she doesn't even think about that, because that's a given. She wants that, but she knows that what her baby needs is also an opportunity to have the best start in life. If they're starting with a mother who's traumatised, the research that I mentioned before, around infant mother bonding, that's going to get—we're going down a pretty—it's not a goodroad. So trauma-informed care, midwifery-led continuity of care and legislation for informed consent—I can give you a list of 10, and I will send that through to you in an email.

RESPONSE

Our 10 Recommendations:

1. **Expansion of access to publicly funded continuity of midwifery carer services** where all LHDs in NSW offer 75% of consumers with this model. This model must be an "all risk" model for women. Women who are categorised as "high risk" must access this model of care and there must be a quota of women accepted into the program from Culturally and Linguistically Diverse Backgrounds. This model should be funded and prioritised to be accessible in all LHDs before the roll-out of the non-evidence-based model of MAPS.
2. **Mandated education and training for Maternity Service staff in the following areas: Trauma-informed** training, **Cultural Safety** training and **Informed Consent** training for all clinicians and health care workers working in maternity services.That these be designed and implemented in hybrid models ie face-to-face and online combined, not just online modules that become a "tick box" compliance training where no culture change will occur.
3. **Legislation on Informed Consent -** In the same way that QLD Health has legislated Informed Consent we must afford women with this in NSW. See above reasons for the imperative to focus on strengthening women's informed consent.
4. **Expansion of Publicly Funded homebirth programs** to the remaining nine Local Health Districts (LHD's) with only five LHD's currently offering this service including the Illawarra Shoalhaven. This should include a review of the exclusion criteria to homebirth.
5. **Dedicated ongoing funding and resourcing of Birthing on Country Programs** including addressing insurance issues for Accredited midwives, increasing the number of First Nations midwives to enable Indigenous midwife-led ,self-determined continuity of care models. Improving outcomes for First Nations mothers and babies in Australia through culturally safe continuity of midwifery care: the time for scale-up is now! - eClinicalMedicine (thelancet.com)
6. **An independent evaluation and audit of the NSQHS Standard 2:Partnering with Consumers**. Consumers and consumer groups are integral to maternity service reform in NSW at both state and LHD level. Ours and many consumer group's experience of Standard 2 is extremely poor. Better health outcomes are guaranteed when consumers actively participate in the care that affects them. They bring strong expertise and lived-experience. Mandating consumer partnerships that include the co-design of key policies, mandating

financial remuneration for consumers and taking special measures to include First Nations and culturally and linguistically diverse peoples and people living with a disability.

7. **Chief Midwifery Officer role** to be created in the NSW Health Ministry following in the steps of Queensland to drive reform in NSW maternity services. We are in a maternity care crisis that requires specialist and dedicated focus.
8. **Retention of midwives be prioritised** and an investigation into the reasons for midwives leaving the profession. Investigating the high attrition rates in Midwifery at university level.
9. Fund **formal Debrief clinics** for women and partners with support from social workers.
10. **Review complaints procedures** in all jurisdictions such that obstacles are removed for CALD families and women receive fair investigations into allegations of mistreatment during the perinatal period.

ENDS