Submission No 877

INQUIRY INTO BIRTH TRAUMA

Organisation: NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors (STARTTS)

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NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors

Submission to NSW Parliamentary Select Committee on Birth Trauma's inquiry into birth trauma

About STARTTS

The NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors (STARTTS) is a non-profit organisation established in 1988 to assist refugee survivors of torture and trauma rebuild their lives in Australia.

STARTTS' services form a part of the NSW public health system through its recognition as an Affiliated Health Organisation (AHO). STARTTS is the NSW member of the Forum of Australian Services for Survivors of Torture and Trauma (FASSTT), with a proud 35-year history of successful services and projects; funded through a variety of government and non-government bodies including NSW Health, and the Commonwealth Departments of Health, Social Services and Home Affairs.

STARTTS' clients are survivors of torture and trauma in the context of organised violence and state terrorism, the majority of whom have arrived in Australia under the Refugee and Humanitarian Program.

STARTTS' service model incorporates a large range of clinical and psycho-social interventions informed by the latest advances in neuroscience and evidence-based practice in relevant fields. Our service provision philosophy is predicated on a bio-psycho-social framework, in recognition of the complex interaction between this essential building block for personal and collective wellbeing, and pre-migration and 'normal life cycle' events post-settlement, which have the potential to impede the recovery of individuals from their traumatic experiences (Aroche & Coello, 1991). As such, our service offer is broad in scope and includes assessment; counselling for all age groups; psychiatric assessment and interventions; family therapy; group interventions; body-focused interventions such as nutrition, massage, physiotherapy, acupuncture and pain management groups; support groups; programs for children and youth; advocacy and policy input; training for service providers; and various strategies to increase the capacity of support networks and refugee communities to sustain their members.

The focus of the STARTTS approach is on building capacity and empowering individuals, families and communities to take control over their own lives and building on individual, family, community and cultural strengths. Furthermore, STARTTS has provided clinical and community development services to over 80,000 individuals for over two decades. Much of this work has been aimed at promoting wellbeing and addressing mental health and psychosocial needs of individuals, families and the communities they are a part of.

Further information about STARTTS' services and programs can be found at http://www.startts.org.au/.

Introduction

STARTTS welcomes the opportunity to contribute to the NSW Parliamentary Select Committee on Birth Trauma's inquiry into birth trauma. Our submission seeks to elevate and prioritise the voices of women from refugee backgrounds, and their experiences of maternity care in NSW. As such, our submission is informed by the following:

- Consultations with STARTTS staff regarding experiences of their clients
- Consultations with nurses and midwives working with women from refugee backgrounds in NSW hospitals
- Consultation facilitated by NSW Health in 2018 with STARTTS clients, which sought to better understand women's experiences of pregnancy care in Australia and identify system changes.

This submission shares direct quotes from these consultations as valuable sources of knowledge and is supported by additional analyses. Our conceptualisation of birth trauma in this submission, encompasses the experiences of trauma that are inclusive of physical and psychological trauma.

This submission provides information on, and addresses the following:

- The experience and prevalence of birth trauma
- The impact of torture and refugee trauma
- Exacerbating factors in delivering and accessing maternity care that impact on birth trauma generally, but also in particular people from refugee backgrounds
- The role and importance of "informed choice" in maternity care
- Other related matters – case examples of effective models
- Recommendations

The experience and prevalence of birth trauma

A mother's experience of obstetric violence amounting to birth trauma during their pregnancy care, can include abusive treatment during birth such as, physical and verbal abuse, lack of informed consent, unconsented medical intervention, failure to comply with confidentiality, refusal of pain medication, disrespect and neglect (WHO, 2014). Such exposure to these practices can have a negative impact for the mother and the baby (WHO, 2014). Further, the adverse effects of obstetric violence can extend to those who are witness to it, including support people, midwives, and other health care professionals (Keedle et al., 2022).

The experience and prevalence of birth trauma and obstetric violence in Australia was highlighted by The Birth Experience Survey (BESt) conducted in 2021. This was one of the largest surveys in Australia that captured women's birthing experiences. The survey sought responses from women who had a baby in Australia in the preceding 5 years. The survey yielded over 12,000 partial responses and over 8,000 completed responses. One in ten of the respondents to the survey reported experiences of obstetric violence, reporting, feeling dehumanised, violated, powerless, bullied and coerced (Keedle et al., 2022). The national survey was in English and had been translated into seven other languages,

including simplified Chinese, Arabic, Hindi, Filipino, Farsi, Thai and Vietnamese. For each language group a cultural steering group was formed to advise and inform the translations (Keedle et al., 2022).

Women from refugee backgrounds are likely to have been underrepresented in this survey due to the limited translations of the survey. To conceptualise this, of humanitarian entrants that arrived in Australia from 2000 – 2014, there were 200 languages and dialects spoken between them, with the highest number of speakers at that time being, Arabic, Dari, Hazaragi, Assyrian, Farsi, Nepali and Karen (FECCA, 2016).

In the majority of cases, women from refugee backgrounds will be unfamiliar with the healthcare system in Australia, while accessing it for their pregnancy. As survivors of torture and refugee trauma they have a specific set of needs that need to be addressed to ensure they have accessible and safe maternal care that does not pose further risk to their wellbeing.

Impact of torture and refugee trauma

STARTTS' clients are survivors of torture and trauma in the context of organised violence and state terrorism, the majority of whom have arrived in Australia under the Refugee and Humanitarian Program or have sought asylum after arriving in Australia. Refugees often experience multiple traumatic events over a prolonged period of time. These events could have happened recently or some time ago. Each person from a refugee background will have their own unique traumatic experiences, however common types of experiences in the context of organised violence can include: prolonged harassment and intimidation, fear of threat and violence, witnessing violent acts, forced separation from loved ones, detainment and imprisonment without trial, killings and disappearances, sexual abuse or rape, attacks, raids and war. Additionally, women and girls are particularly vulnerable and face an increased risk of discrimination, sexual and gender-based violence.

Trauma as a result of previous experiences of organised violence and forced displacement can have a detrimental impact on refugees' ability to rebuild their lives in Australia. Refugees face a complex interaction of challenges when attempting to resettle in a new country. There is a steep learning curve with resettlement tasks as with any migrant (e.g. new culture and system, language, housing, employment, making friends), however this is compounded by the impact of loss, dislocation, grief, torture and refugee trauma, and cultural dissonance (Aroche & Coello, 1994). These impacts of trauma and torture can also be experienced intergenerationally, and with consideration of this, it is necessary for expecting mothers from refugee backgrounds to be provided safe and effective pregnancy care for themselves and their babies (Riggs et al., 2021).

A women's exposure to such stressors and trauma before, after and during birth can contribute to adverse health outcomes such as preterm birth and low birth weight (Riggs et al., 2021). Further, women from refugee backgrounds who have resettled in high income host countries, such as Australia, have markedly poorer perinatal outcomes than woman born in that host country (Yelland et al., 2023). These poorer outcomes have been attributed to healthcare services being unable to address the complexity of a women's social, medical, cultural, and psychological needs which are compounded by communication barriers and the lack or no use of interpreter services (Dube et al., 2023). As a result, women from refugee like backgrounds are reported with higher rates of:

- Postpartum haemorrhage,

- Caesarean section,
- Gestational diabetes,
- Preeclampsia,
- Preterm birth,
- Low birth weight,
- Neonatal nursery admissions (Dube et al., 2023).

In 2021, STARTTS presented a Clinical Masterclass seminar on *Perinatal Psychology and Refugee Trauma: Clinical Implications of the Impact of the Mother's Experiences on the Unborn Baby* with Dr Jennifer Fenwick - Clinical Midwifery Consultant, Gosford Hospital and Naila Hassan – bachelor's degree in counselling and human change, postgraduate diploma in counselling and psychotherapy, master's in counselling and psychotherapy, Early Childhood Counsellor, STARTTS.

This Clinical Masterclass was held in recognition of the need for a discussion on the complexity of the inter-relationship between refugee trauma and birth trauma, and its impact on the in-utero development of the baby. We commend this Clinical Masterclass seminar to the Committee and can provide links to the recording of the seminar.

Our Clinical Masterclass highlighted:

- How epigenetics affects foetal development
- The implications of childbirth related fear, which can increase risk of:
    - preterm and post term birth
    - foetal growth restriction
    - asphyxia
    - emergency caesarean
    - antenatal anxiety
    - distress and depression linked to postnatal depression
    - maternal attachment and infant development problems.
- The implications of birth trauma, which can result in:
    - presentation (or re-presentation) of trauma symptoms after birth
    - extreme pain
    - fear for own life and baby's life.
- Experiences of birth trauma include:
    - violated birth experience/s
    - loss of control
    - health care professionals' use of language, attitudes and care practices
    - medical interventions during labour and birth
    - surgical birth and separation from the baby.

Additionally, our Clinical Masterclass presented the importance of women having access to a safe birthing environment and noted that the modern, biomedical birth spaces commonly used in Australia may not sufficiently create a sense of safety. This is due to the biomedical space commonly functioning as a place for medical interventions to occur, where the woman is under surveillance, with minimum opportunities for privacy, or access to fresh air and scenery. In such an environment, a woman can become passive, hypervigilant and distressed. These notions are further supported in studies

conducted in China, Thailand, New Zealand, and Iran with findings highlighting the influence a woman's birthing environment has on shaping her experience of pain (Whitburn et al., 2019).

With the provision of a safe birthing environment, a woman will see her pain as something that is productive – a goal, working towards something, then her experience of pain may be non-threatening and transformative (Whitburn et al., 2019). However, factors such as communication constraints and the hospital's biomedical space, as mentioned above, can prevent a woman from feeling a sense of, safety, control over her body and support in her birth environment, hindering her ability to cope with that pain (Whitburn et al., 2019).

Exacerbating factors in delivering and accessing maternity care that impact on birth trauma generally, but also in particular people from refugee backgrounds

Australia has one of the highest rates of interventions at birth in a developed country, as well as high levels of childbirth fear and postnatal emotional distress (STARTTS Masterclass, 2021). For women from refugee backgrounds, the fear of childbirth and previous traumatic experiences of childbirth can be interrelated to other experiences of trauma from the refugee experience and contribute to adverse health outcomes (Riggs et al., 2021), as mentioned above.

The Australian Pregnancy Care Guidelines (2020) identifies women from a refugee background as a vulnerable population requiring specific needs, yet the largest model of pregnancy care in hospitals is fragmented, which results in women being seen by different health practitioners throughout their perinatal care (Keedle et al., 2022). This fragmented model of care, coupled with maternal care data system constraints and minimal guidance on how to identify and record a person's migration history, results in women not being identified as being from a refugee background (Yelland et al., 2013). Yet, understanding a woman has a refugee background is an important flag and consideration that there is potentially a trauma history with associated actions required to safeguard that woman from being retraumatised.

In an Australian study by Yelland et al, (2017) that sought to determine ways to improve engagement of professional interpreters for women of refugee backgrounds during their labour, no healthcare professionals involved in the study could recall any specific policies or tailored trainings for working with people from refugee backgrounds. In the same study, from the group of women interviewed who were receiving pregnancy care, only two of the women reported that they were asked by health care professionals if there were any specific cultural practices or customs that were important to be followed (Yelland et al., 2013).

The lack of awareness of a person's refugee experience, previous trauma and cultural considerations can hinder their receival of adequate health care. The following are extracts from STARTTS consultations:

> *A lot of trauma also happens in the postnatal ward. There is a lack of cultural sensitivity, the health care professionals can be mean, dismissive and racist. At times women are being forced to breastfeed without there being a conversation as to why they may not want to be breast feeding, they may have had previous sexual trauma, but this information has not been determined.*

- Nurse

The delivery was traumatic and forceps were used. Mum said that the labour triggered memories of her sexual assault trauma and she had an intense fear of losing her child.
- STARTTS Masterclass client case example

I am aware of a woman with a refugee background that was not provided with trauma-informed care. She had hidden her pregnancy and did not feel able to disclose it earlier. Healthcare staff were also not aware of her history of being pregnant in the past and that the baby had died in utero at 41 weeks. This was only disclosed as she was labouring in her current pregnancy. Because of that history she had to go in for an emergency caesarean as she was at high risk for her labour. During her labour she had family members interpreting for her. In this case, this woman would have benefited from continuity of care.
- Nurse

The role and importance of "informed choice" in maternity care

Approximately 1 in 4 women who give birth in Australia are born overseas, with most coming from non-English speaking backgrounds (Yelland et al., 2017). Women with low English proficiency can experience challenges in freely communicating with their health care provider during their maternal care. As a result, their experience of receiving informed choice and a sense of control and personal agency is hindered, it also limits health care professionals imparting important information and leads to absent or misinformed consent for childbirth interventions (Dube et al., 2023; Yelland et al., 2017).

Through our consultations with STARTTS staff, clients, and health care professionals, it was evident that there is a language policy practice gap in hospital maternal care. The examples provided below involve cases where interpreting services were not used or offered; the heavy reliance of a woman's husband or family member being used to relay information; and women not being aware of what is happening to them, their body and/or their baby.

For some of the people we see from refugee backgrounds, they do not always have the experience of being given a choice due to their history, and having so much of that choice stripped away from them as part of their refugee experience.
- Nurse

There are no face-to-face interpreters available and there is a lack of engaging with phone interpreters – we have been a refugee resettlement town [where the hospital is located] *for over 25 years!*

There is an expectation that the woman brings someone with her who can interpret because otherwise she will not get the language support that she requires.

One woman did not know she was going in for a c-section! The healthcare professionals did not get informed consent from her, she did not know what was happening as they did not use an interpreter.
- STARTTS Staff

So what happened was, because this was her first child and she was squealing in pain from everything the nurses thought that she needed to go into surgery to have a caesarean section. That was not something she wanted, she wanted to say no but it was something she could not explain herself. She did not agree and her husband was nowhere at that time so they had to make a decision and then she had the baby through caesarean section. And then after that, after she had the baby she was tired and had no energy and could not lift her hand up. The nurses told her "you have to treat yourself, don't expect someone to do it". And then she started crying she felt her hand was paralysed she couldn't do much and she didn't have the language to explain that. From her point of view maybe if only her husband was there because he spoke English maybe he could have told the nurses what she wanted and made proper decisions.

- STARTTS Client

There were other reports of experiences where the patient/client were provided with an interpreter which they were not comfortable with engaging with due to the sensitive nature of the discussions or previous negative experiences.

When they gave me the same interpreter I said "please last time I had bad experience with this woman can you give me someone else?" and they say there's nobody else she's the one who does that and when I went to her and said please do not do to me what you did last time I was so sad.

- STARTTS Client

I said "I don't want to answer" [to the interpreter]. I said to him "Can you move?" And he said "I'm not going to move if they don't tell me to go it's my job". I said "I don't want to answer", She [health care professional] said "No you have to", I start crying. She said "No you have to answer, doesn't matter if you cry or not, we have to finish this". I thought "Fuck, what rudeness is this?" I try to answer some but I wasn't comfortable. Up to now, I never been to my community in 9 years I stopped going to my community because when I see him [the interpreter] I start to cry because I didn't feel good that day.

- STARTTS Client

At a birthing suite of a Melbourne hospital, a study was co-designed by a multidisciplinary group, aimed at increasing the engagement and use of professional interpreters for women during their labour (Yelland et al., 2017). The findings of the study showed engagement by women requiring an interpreter increased from 28% to 62% at the ninth month of implementation (Yelland et al., 2017). The study also found that the those who were provided a professional female interpreter for their pregnancy check-up appointments reported having a positive experience (Yelland et al., 2017).

In addition, to promote good birthing outcomes, it would be beneficial for women who have low English proficiency to be provided a qualified interpreter throughout their perinatal journey. Such continuity allows for trust and rapport between the interpreter and woman birthing to be established, which is particularly important during times of heightened stress – and whenever possible, this continuity of interpreter should extend to when the woman is birthing.

Other related matters – case examples of effective models

The following case examples demonstrate different models of care that support women from refugee backgrounds birthing in Australia.

Group pregnancy care is recognised by the World Health Organisation as meeting the needs of populations who are vulnerable to poorer health outcomes, such as those from refugee backgrounds (Riggs et al., 2021). The Australian Pregnancy Care Guidelines (2020) also states the potential benefits of antenatal group care for women from refugee backgrounds. Such models of care offer consistency and can be used to improve cultural safety of maternity care, help reduce experiences of birth trauma, support women who may have past experiences of birth trauma, increase health literacy, provide social support, and improve perinatal outcomes (Riggs et al., 2017).

1) Group pregnancy care in Melbourne, Victoria

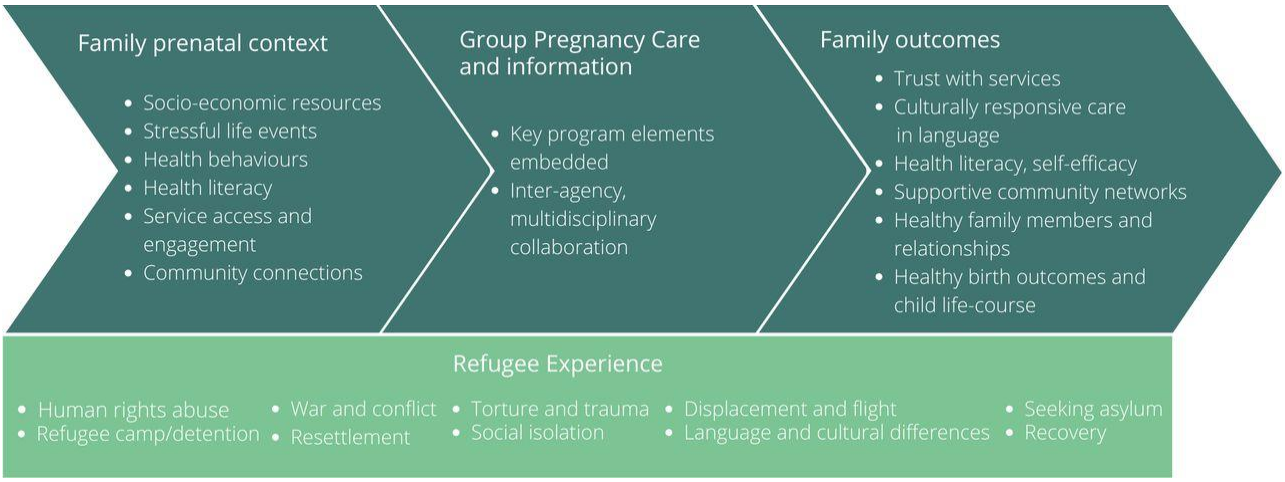
A Group Pregnancy Care (GPC) model was co-designed with a community from a refugee background and other key stakeholders from Melbourne, Australia (Riggs et al., 2021). The aim of the GPC was to increase women from refugee backgrounds engagement with antenatal care, increase their health literacy, overcome language barriers, provide cultural safety, all within a safe and supportive environment (Riggs et al., 2021). The model is delivered by health care professionals and a bicultural worker, that is woman-directed, culturally appropriate and in the women's language. The model extends to facilitating referral pathways for other services including, housing and social work.

The GPC aims to improve the birth and family outcomes for women from refugee backgrounds, the model is underpinned by the Trauma Recovery Framework developed by the Victorian Foundation for Survivors of Torture (2016). The key elements of the GPC model as noted in Riggs et al. (2021), are as follows:

- Local partnerships between public maternity hospitals, maternal and child health services and multicultural agencies. Partnership meetings are held quarterly and both managers and staff are invited to attend.
- Community and stakeholder engagement in the codesign of each new local programme. GPC is tailored to meet the needs of a specific cultural group.
- Establishment of a multidisciplinary team including two midwives, a maternal and child health nurse, a professional interpreter and a community and language-specific bicultural worker; with the same team delivering GPC each session, with designated back-up staff available if needed.
- Women are invited to participate by General Practice referral, hospital booking or through community networks.
- Women-directed group information sessions with women from early to late pregnancy, cofacilitated by a midwife, maternal and child health nurse and a bicultural worker.
- Pregnancy care (as per standard hospital schedule of visits) with a midwife and professional interpreter held at the same time as the group information session.

- Home visits by the same maternal and child health nurse and bicultural worker up to 4 months post-partum (if needed).
- Locating GPC in a community setting close to where families live (eg, maternal and child health centre).
- Flexibility to embed the model in ways that work for communities and health services.

The figure below taken from Riggs et al. (2021) demonstrates how the model aims to bring cultural safety, improve a person's health outcome and self-efficacy. The model also draws on promoting positive outcomes for the whole family.



The following case example draws on a qualitative study of this GPC model that was created in consultation with Karen families living in Melbourne. The GPC model was available for women regardless of the length of their gestation, clinical risk or hospital that they were booked for their birth. The program, as mentioned above, aimed at addressing issues of health literacy and social isolation, whilst allowing the women to come together and share their experiences (Riggs et al., 2017). The GPC was also tailored to increase women's knowledge of English words that would be used during their birth, such as "push".

> *The women reported feeling empowered and confident through learning about pregnancy and childbirth in the group setting. The collective sharing of stories in the facilitated environment allowed women to feel prepared, confident, and reassured, with the greatest benefits coming from storytelling with peers, and developing trusting relationships with a team of professionals, with whom women were able to communicate in their own language. Women also discussed the pivotal role of the bicultural worker in the multidisciplinary care team.* (Riggs et al., 2017)

2) Integrated Refugee Health Service and Refugee Maternity Service

Mater Hospital Brisbane has an Integrated Refugee Health Service and Refugee Maternity Service, that provides health care, resources, and psycho-social support for women from refugee backgrounds. The clinic offers a continuity of care model for a women's perinatal care. The specialised clinic acknowledges the impact of refugee trauma, and presentation of a range or pre-existing medical

conditions that can impact on maternal, foetal and neonatal health, such as malnutrition and female genital mutilation (Mater Health, n.d.).

3) Refugee Midwifery Group Practice

Dubes et al. (2023), studied the effects of a Refugee Midwifery Group Practice (RMGP) in Brisbane, Australia, which provided women from refugee background antenatal group care according to language groups. Of the approximately 460 refugee women who give birth at the hospital every year, approximately 160 of them have access to RMGP. As stated in Dubes et al., (2023), the following is an outline of the program:

- For antenatal care, the women receive continuity of antenatal care and have 24/7 phone access to a known midwife. Antenatal care and education are provided in language groups such as, Somali, Sudanese, Kirundi, Swahili, every two weeks
- Labour and birth care – a birthing room at the hospital; birthing support is provided by the known RMGP
- Postnatal care is provided in the woman's home, by her primary midwife or backup midwife if the other isn't available for 4-6 weeks
- Interpreting services – dedicated onsite interpreters work with midwives and women during group care and education sessions. Face to face and phone interpreters are accessed during antenatal, intrapartum and postnatal period – there is usually a continuity of interpreters
- Cultural safety framework, the RMGP motto is openness to cross cultural learning.
- Group education program that aims to facilitate peer support for women from similar language groups with the aid of an interpreter.
- A social worker on site during antenatal group sessions who is the main point of referral for any social/emotional support or initiating other referrals as required.

Women involved in the program were more likely to have a spontaneous vaginal birth and improved maternal and neonatal outcomes, which is consistent and associated with continuity of care models in pregnancy care (Dubes et al., 2023). Further the study proved the feasibility of the continuity of care model in meeting the needs of women from refugee backgrounds.

Recommendations:

i. Access to continuity of care for pregnant women in NSW is limited. This model of care and group pregnancy care has continuously proven to be feasible and provide more positive health outcomes for women. There is a need to prioritise and increase access to these care models and ensure service delivery is underpinned by a trauma informed framework.

ii. Introduction of specialised services for women from refugee background, with collaborative and co-designed programs available for women in language, such as the GPC models mentioned above.

iii. Implementation of cultural safety training programs for health care professionals, which also increases the understanding of and capacity to respond to interconnected and/or compounding experiences of trauma, including birth trauma.

iv. Increase in bicultural staff in health to support and increase confidence of staff working with diverse clients.

v. Formalised language practice policy to ensure that people accessing maternal health care have open and equitable access to professional interpreters, and wherever possible, continuity of the interpreter service.

vi. Upgrade of equipment in the birthing suites so that they are suitable for non-face to face interpreting services.

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