LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON HEALTH, AGEING AND COMMUNITY SERVICES
Ms Bec Cody MLA (Chair), Mrs Vicki Dunne MLA (Deputy Chair)
Ms Caroline Le Couteur MLA

Submission Cover Sheet

Inquiry into Maternity Services in the ACT

Submission Number: 34

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The Committee Secretary
Standing Committee on Health, Ageing and Community Services
Legislative Assembly for the ACT
GPO Box 1020, CANBERRA ACT 2601
Email: LACommitteeHACS@parliament.act.gov.au

Re: Inquiry into Maternity Services in the ACT

The Health Care Consumers' Association (HCCA) is a health promotion charity and the peak consumer advocacy organisation in the Canberra region. Last year we celebrated forty year of incorporation. HCCA provides a voice for consumers on health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations;
- training in health rights and navigating the health system;
- community forums and information sessions about health services; and
- research into consumer experience of health and human services.

HCCA is a member based organisation and for this submission we consulted with our members and with the HCCA Health Policy Advisory Committee. Our submission draws on experiences shared with us by twelve mothers of babies or young children in the ACT. This submission also draws on discussions with key community organisations including Women With Disabilities ACT. We also draw on research into women's experiences of maternity services conducted by the Women's Centre for Health Matters in 2016, which involved close to 200 women though focus groups as well as a survey of pre-natal, birth and post-natal care in the ACT.[1]

Thank you for the opportunity to put forward consumer views on quality, safety and satisfaction with maternity services in the ACT. Do not hesitate to contact me should you have any queries about the submission.

Yours sincerely

Darlene Cox
Executive Director
1 February 2019

HCCA Submission to the

ACT Legislative Assembly

Inquiry into Maternity Services in the ACT

Submitted 1 February 2019

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Executive Summary

ACT maternity services in context

Pregnancy, child birth and early parenting are normal events. They are also defining experiences for many women and their families. Care that "focuses on a woman's health needs, her expectations and aspirations" is woman-centred,[2] and should be the goal of all maternity services. From the perspective of individual women, woman-centred maternity services offer

- informed choice
- continuity of care, and
- control over what happens to them and their babies.[3]

These elements of care were articulated as part of the foundation for the ACT-wide delivery of maternity services more than 20 years ago.[4] At present, many ACT women and their families receive care with these qualities, and are very satisfied with their care. Like all areas of healthcare, however, opportunities for improvement exist.

Nationally, maternity services face systemic challenges including

- limited access to a range of maternity services outside metropolitan areas,
- unmet demand for home-birth, birth centre and continuity of midwifery care models,
- poorer health outcomes for Aboriginal and Torres Strait Islander women and children when compared to the non-Indigenous population, and
- a high rate of ceasing exclusive breastfeeding within six months of birth.[5]

The ACT is not immune to these challenges. Following the opening of the Centenary Hospital for Women and Children (henceforth, the Centenary Hospital), there was strong demand for services. This led, in part, to negative local media attention in 2017-18 which focused on demand and capacity issues at the new hospital.

HCCA works in partnership with maternity services to ensure a consumer voice in many strategic forums:

- Maternity and Gynaecology Safety and Quality Committee
- Paediatrics Quality and Safety Committee
- ACT Maternity Services Advisory Network
- Women, Youth and Children Divisional Quality and Safety Committee
- Homebirth Governance Committee
- Maternal and Perinatal Information Network.

These forums offer an ongoing opportunity for consumer representatives to raise issues and contribute as partners to quality improvement in maternity services. Based on our experience in these forums, HCCA is confident that ACT maternity services, in general, deliver high quality care. Recent media coverage has heightened public interest in maternity safety and quality issues. This is welcome, as there is room for improvement in any system, and maternity services are no different. Where HCCA cites consumer experiences, which are less than ideal, we do so in the spirit of providing information that can be used to improve the system.

We feel very lucky to have a health system in Canberra and a hospital in Canberra [Centenary Hospital] that is so world class in terms of personnel and care… I didn't experience one staff member that I didn't love and feel completely comfortable with and completely supported by.

This submission

Throughout the submission the term "maternity services" refers collectively to all publicly funded maternity services in the ACT. If we refer to a specific service, we name that service. While this submission focuses on care in the public system, the issues we discuss and our recommendations are also relevant to private maternity services.

HCCA's submission focuses on ***models of care*** (Term a), ***management of patient flow*** (Term c), and ***patient satisfaction with the services*** (Term h). We have chosen to discuss the last with respect to

- aspects of maternity care that women value,
- consumer information for informed decision-making,
- healthy pregnancy,
- labour and birth (including adverse events, birth trauma and involvement of partners and support people), and
- post-natal care and early parenting support.

We also address ***services for socially and economically disadvantaged women, workforce, and data and governance*** matters, which do not appear in the Terms of Reference.

Recommendations

Models of care

- Work towards provision of continuity models of midwifery care as the norm, including for women with higher risk pregnancies
- Make public homebirth one of the models of care easily available
- Bring the eligibility criteria for public homebirth into line with evidence and practice from other Australian jurisdictions
- Expand admitting rights for private midwives in public hospitals
- Address MBS arrangements and indemnity insurance issues that limit access to private homebirth services
- Retain the policy of conducting caesarean sections from 39 weeks gestation unless earlier birth is medically necessary.

Patient flow

- Continue to develop a shared strategy for responding to women's preferences for site of maternity care, supporting women's informed choices, and managing demand for public maternity services.

Patient satisfaction

- Ensure GPs can access up to date information about pregnancy, birth and post-natal care options.
- Continue to support the WCHM to deliver the 'Having a Baby in Canberra' website.
- Work with consumer, community and women's organisations to review and improve existing information about maternity options and explore the option of enhanced face-to-face information sessions for prospective users of maternity services.
- Continue to fund, and promote, initiatives (such as Pregnant Pause) that support healthy pregnancies.
- Continue to practice, promote and train staff in open disclosure and shared decision-making.
- Train and support staff to communicate with consumers about the risks of vaginal tearing, including in ante-natal education classes.
- Implement a trauma-informed approach to maternity services, including staff training and development in trauma-informed care.
- Ensure infrastructure planning responds to women's preference for partners and/or support people to remain with them during and after labour.
- Monitor and review post-natal support services (e.g. MidCall, MACH nursing scheme) to ensure these deliver optimal care to women, babies and families.
- Identify and implement strategies to improve breastfeeding advice and support, including exploring the feasibility of establishing a day stay lactation clinic, resourcing peer breastfeeding support organisations, and working through COAG to advocate for a Medicare rebate for professional lactation consulting services.
- Train health professionals, including GPs, in up-to-date approaches in breastfeeding support and in identifying and managing post-natal depression.

- Involve women in hospital discharge planning, including identifying whether they are ready to leave and a swift pathway to support in the community.

Women experiencing social and economic disadvantage

- Expand the continuity of midwifery care program for women of culturally and linguistically diverse backgrounds**.**
- Prioritise access to public midwifery continuity of care programs for women of culturally and linguistically diverse backgrounds.
- Prioritise ongoing training and development in cultural competency for all staff, including use of a cultural atlas.
- Ensure that women who require interpreting services have access to this service at every appointment.
- Continue and expand support for community-based maternal, child and family health services delivered by community-controlled, Aboriginal, health services.
- Support the development of an Aboriginal and Torres Strait Islander maternity services workforce.
- Enhance continuity of care for Indigenous women in the ACT, particularly transfers between community-based and hospital settings.
- Ensure that care is delivered in places and in ways that are accessible for women with diverse disabilities.
- Provide disability awareness training for professionals delivering maternity services and maternal and child health services.
- Use plain English in all written material.
- Ensure that face-to-face delivery of care happens in ways and places that are accessible to women with a range of disabilities.
- Develop relationship with disability advocacy organisations who support women throughout pregnancy.
- Identify and implement strategies to better support women who are the subject of a child protection notification during their pregnancy.

Workforce

- Train maternity staff in cultural competency, trauma-informed care, open disclosure and shared decision-making.
- Prioritise cultural competency, trauma-informed care, open disclosure and shared decision-making in quality improvement and staff development.
- Train and support staff to communicate with consumers about perineal tearing, including in ante-natal education.

Data and governance

- Release key indicators of maternity safety, quality and health outcomes publicly at regular intervals.
- If quality and safety data indicate that services are performing below the national average in any area, develop and implement a plan to improve care, involving women in the governance of these initiatives.
- Retain and strengthen processes for consumer involvement in governance and strategic planning.

Models of care – Term of Reference (a)

Models of care for all maternity services offered at the Centenary Hospital for Women and Children (CHWC) and Calvary Public Hospital (CPH), including, but not limited to, the Birth Centre, the Canberra Midwifery Program, and the Home Birth Trial and whether there are any gaps in care;

Key points

- ACT maternity services offer a variety of safe, high quality models of care
- HCCA supports the expansion of continuity of midwifery care models
- HCCA would like to see public home birth become more readily available to women.
- HCCA supports expanded opportunities for private midwives to admit and care for women while in a public hospital.
- HCCA supports Canberra Health Services' policy of not booking planned caesarean sections before 39 weeks gestation.
- HCCA encourages maternity services to explore opportunities to support women to access VBAC where it is safe to do so.
- Later in this submission (page 15), HCCA recommends that continuity of midwifery care be offered as standard care to socially and economically disadvantaged women and women at risk of poor maternal and child health outcomes.

Continuity of midwifery care

Continuity of care from a known and trusted primary provider (midwife, GP, obstetrician) supports the delivery of safe, high quality and woman-centred care.[6] Continuity of midwifery care has been shown to deliver better maternal and child health outcomes and is associated with enhanced positive experiences of care.[7] HCCA strongly supports the aim of "increasing access to continuity of midwifery care".[8]

Currently, a minority of women in the ACT receive continuity of midwifery care.[9] Continuity of care from a known primary midwife is one of the features of the ACT Birth Centres that many women value highly. To HCCA's knowledge CatCH (Continuity of Care at Canberra Hospital) is the sole program offering continuity of midwifery led care to women with higher risk pregnancies in the ACT. There is a perception in the community that continuity of midwifery care is not suitable for women who have a need or preference for higher intervention during birth or who wish to access pharmacological pain relief.[10]

One woman who spoke with HCCA had engaged a private homebirth midwife, hoping to give birth to her third child at home in NSW. When she developed gestational diabetes, she agreed with her midwife that it would be too difficult to manage the immediate post-partum period at home. She is now receiving obstetric and group midwifery care at Centenary Hospital. She's continued to engage her private midwife, as she finds it useful to talk with her after each appointment at the hospital. She knows her caregivers at the hospital are highly skilled, but she finds it is difficult to know what the plan for her care is. She values the continuity and personalised care that her private midwife offers. She thinks that "continuity is even more important when you are high risk", because of the anxiety that can come with additional health issues in pregnancy and the need for extra information.

Recommendation: Work towards provision of continuity models of midwifery care as the norm in the ACT, including for women with higher risk pregnancies.

Homebirth

Publicly funded homebirth is offered in most Australian jurisdictions. The ACT began a public homebirth trial in 2016 and HCCA looks forward to the public release of its evaluation. If the evidence confirms that this is a safe and high-quality service for women and families, HCCA strongly supports making the service a permanent feature of ACT maternity services. Currently, the eligibility criteria are highly restrictive, including being limited to low risk pregnancies and women living within 15 minutes travel time of the Centenary Hospital.[11] We would like to see these criteria brought into line with evidence and practice from other Australian jurisdictions and internationally.

Another way to support women who wish to have a homebirth is to expand the opportunities for private midwives to admit and care for women who may need to be admitted in unforeseen circumstances in public hospitals. This will also improve continuity of midwifery care.

HCCA recognises that the cost of private home birth is prohibitive for many women. And we encourage the ACT Government to work through COAG to address Medicare Benefits Schedule (MBS) arrangements and indemnity insurance, which would increase access to private homebirth for women and their families.

Recommendation: Make public homebirth one of the models of care easily available to ACT women.

Recommendation: Bring the eligibility criteria for public homebirth into line with evidence and practice from other Australian jurisdictions.

Recommendation: Expand admitting rights for private midwives in public hospitals.

Recommendation: Address MBS arrangements and indemnity insurance issues that limit access to private homebirth services.

Planned caesarean section

Recent research has found that that planned caesarean section before 39 weeks is accompanied by a higher risk of short-term adverse health impacts on babies (including respiratory distress, hypoglycaemia and jaundice). There is also evidence that it can lead to poor longer-term developmental impacts through childhood.[12] Based on this research, the 2018 Australian Atlas of Health Care Variation recently recommended that planned caesarean section should not take place before 39 weeks unless there is a medical reason for earlier birth.[13] HCCA supports the Health Directorate's policy of booking all elective caesarean sections for no earlier than 39 weeks gestation unless there is an obstetric or medical indication for earlier delivery. HCCA also encourages maternity services to ensure they have processes to document the evidence that each early planned caesarean performed is medically necessary.

Recommendation: Retain the policy of conducting caesarean sections from 39 weeks gestation unless earlier birth is medically necessary.

Management of patient flow – Term of Reference (c)

Management of patient flow, including, but not limited to, wait lists, booking services, and capacity constraints;

Key Points

- Women perceive that Centenary Hospital staff and services work under significant pressure. While many women value the professionalism and excellent patient care offered by busy staff, in a minority of instances women report that this impacts negatively on their care.
- HCCA supports Centenary Hospital and Calvary Public Hospitals' increased efforts to jointly respond to demand for maternity services.

I feel very warm and friendly towards the TCH maternity section and I feel like it's not given the kudos it deserves. Any criticism I would have comes down to, there is a feeling of pressure, in terms of the beds and the staff, but that's not reflected at all in the care. They deal with that [pressure] phenomenally.

Demand for maternity services

In 2016 the Women's Centre for Health Matters reported that many women have a preference to birth and receive care at the Centenary Hospital because

- it is newly opened, with comfortable facilities that are perceived to be the most modern and comfortable available, and
- as a tertiary referral hospital, it has capacity to deal with a complicated birth.[14]

The Centenary Hospital also offers a broader range of models of care, including the CatCH program and public funded homebirth trial. Additionally, some women have reported that the religious ethos of Calvary Public Hospital is not a comfortable fit with their personal values.

One woman who recently moved from interstate and did not know ACT services well told HCCA that she chose to receive care at Centenary Hospital even though she lives a five-minute drive from Calvary Hospital. She is "not a religious person" and after driving around the Calvary campus found the large cross on one of the buildings off-putting and thought care at the hospital "just wasn't for me".

Several women who spoke with HCCA observed that staff and services at the Centenary Hospital were busy and appeared to be managing significant demand. In almost all cases women felt that the hospital and its staff managed these demands without negative impact on patient care or experiences.

One woman told HCCA that:

They would have had me induced if they had enough staff, but instead they sent me home and told me what [signs of infection] to look out for [after my waters had broken]. I didn't feel at all unsupported or mistreated, there just weren't enough staff, but the staff were empathetic because I was clearly worried. They offered for me to stay in hospital and be monitored overnight but that it would probably be better for me to go home and rest. You can sense that there's pressure, but… the staff were 100 per cent positive and supportive. I never felt that they rushed me or made me feel like a burden to a stressed system.

Another woman who spoke to HCCA laboured at Calvary Hospital in 2010.

The birth suite was full, and I was installed in a spare treatment room on the ward to deliver. This resulted in a verbal confrontation regarding appropriate protocol between staff, which occurred over my body whilst I was in an obstructed labour. Eventually I was admitted to the birth suite and scheduled for an emergency C-section, with relatively little explanation of why this was required. Following the C-section I was accommodated on the private side of the ward for a few hours due to lack of space, then moved into a 4-bed public ward, where I received care from midwives, one of whom worked a 16 hour shift. I feel that staff conflict due to understaffing and lack of physical infrastructure hugely contributed to the lack of trust and confidence I felt in the staff and the overall negative experience".

HCCA understands that the Centenary Hospital and Calvary Public Hospital are working together, with consumer input, to develop a shared approach to managing demand for maternity services. HCCA supports the principle that public maternity services should be offered as close to home as possible. However, this should be balanced with respect for any valid reasons why women prefer to receive care at one or other of the ACT's public hospitals. Centenary Hospital and Calvary Public Hospital's joint work to respond to demand for maternity services has the potential to support women's informed choices in relation to both site and model of care. The recent refurbishment of Calvary Public Hospital's maternity ward may also enhance women's perception of the care and amenity offered there.

Recommendation: Continue to develop a shared strategy for responding to women's preferences for site of maternity care, supporting women's informed choices, and managing demand for public maternity services.

Patient Satisfaction – Term of Reference (h)

Patient satisfaction with the services;

Key points

Many women and families have very positive experiences of ACT maternity services. As in all areas of health service delivery, opportunities to improve levels of satisfaction exist:

- Provision of additional consumer information about pregnancy care options
- Continuation of programs that support women to have healthy pregnancies, for example ceasing drinking alcohol
- Supporting all maternity services professionals to practice shared decision-making and trauma-informed care
- Addressing perineal tearing and management during ante-natal education
- Infrastructure planning that priorities opportunities for partners and support people to remain with women and new-born babies where this is the mother's preference
- Further strengthening post-natal support to establish breastfeeding and identify post-natal mental health issues

Aspects of maternity services women value

While not all the women who shared their stories with HCCA had positive experiences, many of the women we spoke to valued:

- the skill, professionalism and care of maternity professionals,
- the diverse models of care offered
- the amenity offered by the ACT's public hospitals,
- the safe and high-quality care they received, and
- the practice of open disclosure and good communication after an adverse event or complicated birth.

Skilled, professional and caring staff

I always felt supported [at the Centenary Hospital]. There were always qualified people on hand to answer my questions. We have had a very good experience and I just felt supported by the system. Appointments were always on time. Everything was good. The parking is obviously an issue at maternity, but that's not insurmountable.

I feel like the Birth Centre midwife was very professional, very professional, warm but not over friendly and able to answer all my questions and provide information in a really concise way. I liked her demeanour. She was very forthcoming with information.

Amenity

One woman told HCCA that she appreciated the privacy and quiet at Centenary Hospital. In the UK public hospital where one of her children was born, she shared a maternity ward with 8 women, their newborn babies and their visitors. They shared a shower and toilet with another 8-bed ward, located down a corridor. She thinks when it comes to amenity, "TCH is pretty good with that side of things".

Safe, high quality care

One woman, whose first baby was born very pre-term, told HCCA that:

The best care was given to both me and my son in that time. That set the tone for all my experiences at TCH although it was a very traumatic time for us, very grave. We always had this sense that the absolute best care was being given to him 24 hours a day whether we were there or not. We had wonderful professional relationships with all the nurses and doctors on the ward and we had fantastic ongoing continuity of care with the doctors, the nurses and all the external services, MACH nurses, physio, eye doctors. We actually came away feeling that an experience that could have been very jarring and scarring…. I feel so grateful … the care there is what changed everything for us.

When women's experiences were less positive, it was often because they did not have opportunities to be involved in decision-making or did not feel in control of what was happening to them and their babies. These less positive experiences highlight some areas for potential quality improvement, which are discussed below.

Consumer information for informed decision-making

In order to make informed decisions about which model of care is appropriate, women need trustworthy and comprehensive information about which services would best match their preferences and situation. This information supports women and families to be partners in their own care, a goal that health services work toward under National Safety and Quality Health Service Standard 2, Partnering with Consumers.

One woman discovered she had diabetes shortly before becoming pregnant. Her pregnancy was considered high risk due to this and other factors, and she was uncertain where to go for care and where to seek advice about her choices. Her GP was *"not particularly helpful*". She could not understand why some practices and assessments of risk to her seemed to vary between the public and private systems.

The 'Having a Baby in Canberra' website managed by the Women's Centre for Health Matters collates information about maternity care services and options in one place. This is a valuable resource for women and could be more widely promoted including to GPs and to the community. As the first point of contact with maternity services for many women, it is important that GPs can provide women with up-to-date information about maternity care options. The Health Directorate could also review the information about maternity care options available on their website, with input from women, and consider providing this information in other formats for example community information sessions.

Recommendation: Ensure GPs have access to up to date information about pregnancy, birth and post-natal care options.

Recommendation: Continue to support the WCMH to deliver the 'Having a Baby in Canberra' website

Recommendation: Work with consumer, community and women's organisations to review and improve existing information about maternity options, and explore the option of enhanced face-to-face information sessions for prospective users of maternity services.

Healthy pregnancy

ACT Health currently fund and promote preventative health campaigns such as Pregnant Pause, which encourages other family members to support the woman by also not drinking during her pregnancy.

Investment could be made into campaigns like Pregnant Pausea that encourage other family members to support the woman by also not drinking during her pregnancy. This may reduce feelings of social exclusion.

Recommendation: Continue to fund, and promote, initiatives (such as Pregnant Pause) that support healthy pregnancies.

Labour and birth

Adverse events and complicated births

Adverse events, complicated births and birth trauma affect some women and families in all health systems. Women and their families are more likely to be satisfied with the service's response if their caregivers acknowledge the issue, apologise swiftly and welcome a frank conversation about how the event was handled. This approach to adverse events is recognised as best practice,[15] and can contribute to recovery and healing for women who experience traumatic birth.[16]

I can understand how women could feel traumatised because of not having enough information about what goes wrong, but I felt like I had full access to the professionals involved [after I experienced an adverse event in labour], who came specifically to talk to me about whether I was upset about having the [emergency] Caesar and why they had to do the Caesar, so I don't feel that at all.

One woman who spoke to HCCA tore during her labour. A nurse and two doctors worked on the suturing before a fourth doctor decided that she should be re-stitched. This required a general anaesthetic. The next morning the doctor who did the original suturing and the doctor who re-did the stitches came to see her together. The original doctor apologised profusely, and them mother was somewhat mollified that he did.

Perineal tearing affects many women and can be traumatic. One woman told HCCA that she felt the possibility of tearing was "glossed over" in birth education classes at the Centenary Hospital, perhaps in an effort not to frighten women. In her view, open discussion in pregnancy about the risk of tearing, strategies to minimise this risk, and information about the clinical management of tears would help to normalise this aspect of birth, and may assist women to recover from physical or psychological trauma associated with tearing.

Given the increasing evidence that birth trauma can have significant negative impacts on maternal and child health, including an increased risk of post-natal mental health concerns, ACT maternity services should consider how they can adopt a more explicitly trauma-informed approach to the care they deliver. Trauma-informed services seek "safety first" and commit themselves to "do no harm".[17] All aspects of the service are informed by the recognition and acknowledgement of trauma, an understanding of its prevalence, and an awareness of, and sensitivity to, its dynamics.[18] Thus a trauma-informed care and practice approach meets the physical, emotional and psychological needs of consumers, and is responsive to an individual's unique circumstances and goals, thereby constituting ideal consumer-centred care.[19]

Women are more likely to experience birth trauma when they do not feel that they have been involved in decisions about their care.[20] Shared decision-making, where consumers have opportunities to take part in discussions and decisions about their care, is therefore particularly important in maternity services. Women and parents who spoke to HCCA, and had opportunities to participate in shared decision-making, were much more satisfied with their experiences than those who did not.

Recommendation: Continue to practice, promote and train staff in open disclosure and shared decision-making.

Recommendation: Train and support staff to better communicate with women about tearing, including in ante-natal education classes.

Recommendation: Implement a trauma-informed approach to maternity services, including staff training and development in trauma-informed care.

Involving partners and support people

Many women would like their partners or other support people to be actively involved in supporting them during labour and in the immediate post-natal period. The interior architecture of maternity spaces do not always support this option. Some families are not able to stay together after a child is born, due to lack of space and other environmental issues.

A woman who birthed her daughter in 2017 recalls that the atmosphere at Centenary Hospital's maternity ward was very warm and caring. However, her husband was not considered an essential part of the birthing process. It was fortunate that she and her husband insisted he stay with her after she was induced, because their daughter was born four hours later. She needed and wanted her husband with her and thinks this should be accommodated within a maternity ward.

Recommendation: Ensure infrastructure design responds to women's' preference for partners anor support people to remain with them during and after labour.

Post-natal care and early parenting

Many women and families have positive experiences of post-natal care and support. However, there are opportunities to further strengthen services in this area.

It is lovely to be discharged early if you have the support you need in the community.

Breastfeeding support

Women's preference for length of stay in hospital after birth vary significantly. Some would prefer to receive peri-natal care and early parenting support in home and community settings. However, the Women's Centre for Health Matters found that many women who gave birth in hospital wanted to stay longer than 24 hours, in particular to establish breastfeeding. These women felt that they were discharged without enough access to help and support in hospital to establish breastfeeding, and insufficient access to timely assistance from appropriately skilled health professionals in the community. Some women struggled with confusing and contradictory advice about breastfeeding from health professionals and were not sure where to go for support.[21]

There was pressure to leave [hospital]. They offered for us to stay but the sense you get is that you should go. If you think logically about it, it's probably good to go home, you don't want to be in a hospital where they're people who are sick and you probably should want to get home. But I didn't feel I had established breastfeeding and I was a bit worried about going home, generally. But when we came home we were visited by Midcall for the next three day, which was really reassuring. That was a really good service.

One woman told HCCA that she was very keen to breastfeed her first baby. Her ante-natal classes at a public hospital had emphasised the benefits of breastfeeding for child development. She was "devastated" when a Maternal and Child Health (MACH) nurse told her that her baby's brain might not develop normally because she was not producing enough milk. She called a community-based, peer-led breastfeeding counselling service several times, but the line was busy with other callers. Eventually with her GP's encouragement she moved to supplementary feeding, which she thinks was a good decision for her and her baby.

Post-natal depression and anxiety

There may be opportunities to identify signs of post-natal depression and anxiety earlier.

One woman told HCCA that she received excellent care in pregnancy and labour, including superb management of a chronic condition that placed her and her baby at higher risk of serious complications. However, she believes her early signs of post-partum depression were overlooked in hospital and that she would have benefitted from more assistance to establish breastfeeding. Her post-natal depression wasn't diagnosed until her daughter was nine months old. She did attend the QEII Family Centre and found this "life changing".

The only thing I was disappointed didn't happen, when I was in The Canberra Hospital, was my request to talk to someone about my anxiety about breastfeeding and coping with anxiety once I left the hospital. This was purely due to the demands on the psychology team and not being able to get to me in time before I left the hospital. I received a phone call a few weeks later. Obviously not helpful! However, I have to say that I was able to stay until I felt ready to leave. I was not 'pushed out' early by any means.

The Women's Centre for Health Matters' 2016 research into women's experiences of maternity services concluded that "with shorter hospital stays there is a need for increased support in the home following discharge from hospital during the postnatal period".[22] HCCA would welcome an expansion of the support available to women and families in the immediate post-natal period.

Recommendation: Monitor and review post-natal support services (e.g. MidCall, MACH nursing scheme) to ensure these deliver optimal care to women, babies and families.

Recommendation: Identify and implement strategies to improve breastfeeding advice and support, including exploring the feasibility of establishing a day stay lactation clinic for the ACT, resourcing peer breastfeeding support organisations, and working through COAG to advocate for a Medicare rebate for professional lactation consulting services.

Recommendation: Train health professionals, including GPs, in up-to-date approaches in breastfeeding support and identifying post-natal depression.

Recommendation: Involve women in hospital discharge planning, including identifying whether they are ready to leave and a swift pathway to support in the community.

Services for socially and economically disadvantaged women

Nation-wide there is a recognised gap in access to continuity of care models for women of culturally and linguistically diverse backgrounds and women living with social or economic disadvantage. HCCA supports the Victorian Inquiry into Peri-natal Care's recommendation that culturally and linguistically diverse women, Aboriginal and Torres Strait Islander women and women who are socio-economically disadvantaged should have priority access to culturally sensitive, continuity of midwifery care programs.[23]

Women from culturally and linguistically diverse backgrounds

Cultural competence is a key characteristic of high performing maternity services, and an essential aspect of woman-centred care. It is the ability to interact effectively with people of different cultures.[24] This means that systems and the people within them work effectively in cross-cultural situations, and value culture in the delivery of services to all segments of the population.[25] Almost half of all people in Australia (49%) were either been born overseas or have at least one overseas-born parent,[26] cultural competence is a fundamental requirement for all health professionals and health services.

A systematic review of women's experiences of accessing sexual and reproductive health care in Australian showed that women from culturally and linguistically diverse backgrounds experience substantial difficulties in accessing sexual and reproductive health information and services in Australia. This includes the provision of information on the health services available to them, health education opportunities, hospital policies and clinical procedures.[27] Things that facilitated use of health services include being connected with a community case worker, having mentors from the same cultural background, having appointments made for them when they received home visits from refugee health nurses, access to bilingual staff, co-location of services, and home visits by refugee health nurses.[28]

Women from culturally and linguistically diverse backgrounds in Australia have expressed concerns about healthcare providers who do not have knowledge about their cultural norms and traditions[29] and religious beliefs.[30] Cultural training for health professionals is recommended.[31]

A lack of information on the availability of translating services, and materials in their first language is a barrier to many women.[32] While they feel that interpreters help facilitate their access to necessary services[33] some studies report that it takes too long to arrange an interpreter to assist them.[34,35]

Culturally and linguistically diverse women can experience social isolation and do not always feel welcome using maternity services, or maternal and child health services. Nor do health professionals always know how best to communicate and work with women, and there is a recognised gap nationally in the use of interpreting and translating services.[36]

Recommendation: Expand continuity of midwifery care program for women for women of culturally and linguistically diverse backgrounds

Recommendation: Prioritise access to public midwifery continuity of care programs for women of culturally and linguistically diverse backgrounds.

Recommendation: Prioritise ongoing training and development in cultural competency for all staff, including use of a cultural atlas.

Recommendation: Ensure that women who require interpreting services have access to this service at every appointment.

Aboriginal and Torres Strait Islander women

There are many barriers to accessing healthcare for Aboriginal and Torres Strait Islander women. Evidence given and tabled at the Victorian Inquiry into Perinatal Services included:

- intergenerational trauma and the fear of having their children taken away,
- the cost of accessing services,
- a lack of culturally appropriate services,
- homelessness,
- drug and alcohol abuse,
- domestic violence issues,
- isolation, and
- a fear of judgement from health providers.[37]

In specific recognition of the population health inequality that affects Aboriginal and Torres Strait Islander women, HCCA recommends that the ACT Government work with Aboriginal health care organisations and representative bodies to undertake the following work.

Recommendation: Continue and expand support for community-based maternal, child and family health services delivered by community-controlled, Aboriginal, health services.

Recommendation: Support the development of an Aboriginal and Torres Strait Islander maternity services workforce.

Recommendation: Enhance continuity of care for Indigenous women in the ACT, particularly transfers between community-based and hospital settings.

Women with disabilities

Women with disabilities in the ACT can face specific challenges when using health services, including maternity services. There is an ongoing need for maternity services to ensure that care is accessible and appropriate for women with disabilities. Women with disabilities deserve to receive the same woman-centred care available to others.

Like all pregnant women, those with disabilities need to attend appointments and ante-natal classes. However, the choice of location can prevent or make attendance difficult. For instance, rooms need to be physically accessible for women who use a wheelchair. Similarly, the means of presenting the information can preclude participation by women with impaired hearing or vision. As a matter of environmental literacy, all materials should be written in plain English. Additionally, it may be required in braille, able to be read by a screen reader, or extra-large font. Others may require a sign language interpreter to accompany them. Women also need to be given the time and opportunity to frame and ask questions at appointments and classes.

The nature of their disabilities should not preclude women from participating as essential partners in safety and quality. Consumer advocacy and community organisations play a critical role in ensuring women with disabilities have opportunities

- to raise issues of concern to them in relation to their care,
- to express their preferences for care, and
- to participate in feedback and complaints processes.

These organisations need to be publicly supported to continue this valuable work.

Recommendation: Ensure that care is delivered in places and in ways that are accessible for women with diverse disabilities.

Recommendation: Provide disability awareness training for professionals delivering maternity services and maternal and child health services.

Recommendation: Use plain English in all written material.

Recommendation: Ensure that face-to-face delivery of care happens in ways and places that are accessible to women with a range of disabilities.

Recommendation: Develop relationship with disability advocacy organisations who support women throughout pregnancy.

Women and children involved in the child protection system

ACT health professionals are required by law to make a pre-natal report to ACT child protection authorities if they are concerned that an unborn child is at risk of abuse or neglect after birth. This practice can undermine the trust between a woman and her caregivers during pregnancy, and can lead to women's disengagement with pre-natal care services. Once a pre-natal report is made about a woman, her pregnancy may end with the removal of her baby from her care at birth. In many instances this outcome could be avoided if appropriate support services were made available to the woman. Given the over-representation of Aboriginal and Torres Strait Islander families and young people in the out-of-home care system, it seems probable that the practice of removal at birth disproportionately affects Aboriginal and Torres Strait Islander mothers, babies and families.

Currently in the ACT there is a lack of early intervention and support for families who have come to the attention of child protection agencies,[38] and there is a specific lack of coordinated, culturally competent, health and social care for women who are the subject of child protection notification during pregnancy. Women and families whose children are removed at birth face complex, unclear and gruelling legal processes if they chose to seek the return of their children.[39] HCCA is concerned that these women and their families are being punished for structural circumstances beyond their control. The lack of appropriate support to avoid this outcome is iniquitous, given the clear evidence that involvement in the care and protection system risks significant further harm to young people.[40]

HCCA believes that the removal of children by child protection agencies should occur as a last resort. Opportunities exist for the ACT Government and maternity services to provide better care for women and families who are the subject of child protection notification in pregnancy. The work that has already arisen from the *Our Booris Our Way* review suggests a number of ways to improve care.[41] For example,

- enhancing pre- and post-natal family and decision-making support, and
- removing child protection and health care practices that reflect the assumption that removal is inevitable.

Recommendation: Identify and implement strategies to better support women who are the subject of a child protection notification during their pregnancy.

Workforce

Drawing on discussion elsewhere in this submission, HCCA makes the following recommendations in relation to workforce development and training.

Recommendation: Train maternity staff in cultural competency, trauma-informed care, open disclosure and shared decision-making.

Recommendation: Prioritise cultural competency, trauma-informed care, open disclosure and shared decision-making in quality improvement and staff development.

Recommendation: Train and support staff to communicate with consumers about perineal tearing, including in ante-natal education.

Data and governance

Using data for quality and safety

Health services that share data about their performance with the public at regular and predictable intervals make quality and safety improvements more swiftly than services that do not and are better able to document the outcomes of their continuous improvement processes.[42] HCCA encourages maternity services to identify quality and safety data for regular public release.

HCCA understands that all ACT public maternity hospitals participate in data collection and benchmarking activities conducted by Women's and Children's Hospitals Australasia. This longitudinal dataset includes information about activity (for example, the number of births in different models of care) and health outcomes (such as post-birth complications e.g. haemorrhage). While this data currently supports internal quality improvement activities within ACT maternity services, it could also be a valuable source of information for consumers. This data would inform public and media debate about safety and quality in maternity services, support public confidence and trust in maternity services, and support women's informed choices in relation to maternity care.

Recommendation: Release key indicators of maternity safety, quality and health outcomes publicly at regular intervals.

Recommendation: If quality and safety data indicate that services are performing below the national average in any area, develop and implement a plan to improve care, involving women in the governance of these initiatives.

Consumer involvement in governance

Consumer involvement in health service governance supports the delivery of safe, high quality health care,[43] and is a requirement of Standard 2 of the National Safety and Quality Health Service Standards. Several of the ACT's maternity and peri-natal services have well-established processes for consumer involvement in governance and strategic decision-making, for example through consumer representation to the

- Maternity and Gynaecology Safety and Quality Committee
- Paediatrics Quality and Safety Committee
- ACT Maternity Services Advisory Network
- Maternity Quality and Safety Committee
- Women, Youth and Children Divisional Quality and Safety Committee

These processes create a strong foundation for continued quality improvement across the ACT's maternity services.

Recommendation: Retain and strengthen processes for consumer involvement in governance and strategic planning.

Concluding remarks

Thank you for the opportunity to bring consumer issues to the attention of the Inquiry. HCCA looks forward to the outcomes of this process and welcomes any questions members of the Committee may have.

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