Chapter 6

Improving quality of care

6.1 Recent Australian and international research on stillbirths, including inquiries into cases of substandard care, has shown that many stillbirths are preventable and that the number of deaths can be reduced through improved quality of care. According to the Centre of Research Excellence in Stillbirth (Stillbirth CRE), deficiencies in the quality of care in pregnancy and labour are implicated in 20–30 per cent of all stillbirths.[1]

6.2 The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) stated that the 'model of care directly influences the risk of perinatal death'. Antenatal care, for example, increases the probability that fetal growth restriction (FGR) will be identified before labour.[2] In 2013–14, women who accessed six or more antenatal visits were associated with a lower stillbirth rate than women who accessed fewer antenatal visits or had not accessed antenatal care at all.[3]

6.3 Nevertheless, there is no agreement amongst health professionals as to the most appropriate models of care in relation to stillbirth, and several submitters proposed that further research is needed in this area, particularly for women who may be at higher risk of stillbirth.[4]

6.4 This chapter examines quality of antenatal and bereavement care in relation to stillbirth, including culturally and linguistically appropriate models of care.

Continuity of care

6.5 There are different models of care for women in the perinatal period, including hospital clinic care, shared maternity care, team midwifery care, midwifery-led continuity of care, and planned homebirths.

6.6 Continuity of midwifery care is a strong traditional practice in parts of Europe including The Netherlands and Scandinavia. New Zealand has also adopted a midwifery care model, whereby about 80 per cent of women choose a midwife as their lead maternity carer and give birth at home, in a small midwifery-led unit or in a

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1 Centre of Research Excellence in Stillbirth (Stillbirth CRE), *Submission 56*, pp. 4–5.

2 The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), *Submission 17*, [pp. 2–3].

3 Australian Institute of Health and Welfare, *Perinatal Deaths in Australia 2013-2014*, 31 May 2018, p. 30.

4 See for example Australian College of Midwives, *Submission 24*, [p. 10]; Hunter Medical Research Institute, *Submission 36*, [p. 3]; Professor Jane Dahlstrom, *Submission 128*, p. 3.

district or major hospital. Canada is also beginning to invest in employing midwives in hospitals to provide continuity of care.[5]

6.7 Professor Caroline Homer, Distinguished Professor of Midwifery, Centre for Midwifery, Child and Family Health, University of Technology Sydney, estimated that 10 per cent of Australian women receive continuity of midwifery care, while 25 per cent choose private obstetrician-led care. She noted that some hospitals are shifting to the continuity of care model, but these tend to be isolated examples.[6]

> We now know from very good research from around the world, half of which was collected in Australia, that midwifery continuity of care will make a difference. If women see the same few midwives throughout their pregnancy, they will know those, usually, women during labour and birth, they will have fewer preterm births, they will be less likely to lose their babies, they will have a much more positive experience, and they will have fewer labour and birth interventions. It is not happening across the country. There are pockets of exemplary practice, but it is not widespread, despite policy at a state level. It is less so at a national level at the moment...I think there's a lack of political mandate, a lack of resourcing and a lack of understanding that continuity of care will save money in the long term.[7]

6.8 Therefore, health care for most pregnant women in Australia is fragmented, resulting in multiple caregivers throughout pregnancy. Ms Annie Butler, Federal Secretary, Australian Nursing and Midwifery Federation, noted that midwifery care models are known to be effective, particularly for women who experience stillbirth.

> A 2016 Cochrane review conducted by Sandall et al highlighted that women were less likely to lose their baby before 24 weeks when they received models of midwife-led continuity of care. Midwifery continuity of care models have a strong evidence base in best supporting women with past trauma including stillbirth. Having a known midwife results in women experiencing greater support and decreasing their anxieties and unnecessary use of diagnostics and interventions.[8]

6.9 Some witnesses argued that continuity of care is important throughout pregnancy in building trust and understanding and enabling conversations that include the subject of stillbirth.[9] The Australian College of Midwives cited research showing

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5 Professor Caroline Homer, Distinguished Professor of Midwifery, Centre for Midwifery, Child and Family Health, University of Technology Sydney (UTS), *Committee Hansard*, 8 August 2018, p. 34.

6 Professor Homer, UTS, *Committee Hansard*, 8 August 2018, p. 33.

7 Professor Homer, UTS, *Committee Hansard*, 8 August 2018, pp. 33−34.

8 Ms Annie Butler, Federal Secretary, Australian Nursing and Midwifery Federation, *Committee Hansard*, 9 August 2018, p. 56; Australian Nursing and Midwifery Federation, *Submission 58*, p. 2.

9 For example, Ms Natasha Donnolley, *Committee Hansard*, 8 August 2018, p. 4; Australian College of Midwives, *Submission 24*, [p. 4]; Australian Nursing and Midwifery Federation, *Submission 58*, p. 2; Confidential, *Submission 261*, p. 5.

that a continuity of care model, delivered by midwives, can reduce the rate of stillbirths.[10]

6.10 Professor Michael Permezel, Immediate Past President, RANZCOG, considered that a collaborative model of care where midwives and obstetricians work together as a team, rather than 'obstetrician-led' care, is the most effective model for lowering perinatal risk.[11] Professor Homer suggested that such a model has been implemented in some places because of local will and enthusiasm as well as political leadership, but she noted that there are lingering issues that present barriers to continuity of care being introduced across Australia.

> People always bring up the turf wars between midwives and obstetricians, and I think that's actually less of an issue in public services. Obstetricians generally want to look after complicated women in public services, not normal, straightforward women, and, when they've got complications, they want midwives with them because it enhances the whole care.[12]

6.11 Stillbirth CRE proposed that a review of maternity services should be undertaken, focusing on ensuring that all women have a continuity of care provider, whether a midwife, a GP obstetrician or a specialist obstetrician.[13]

6.12 In this context, Stillbirth CRE noted that it was developing a 'bundle of care' program for Australian hospitals, in partnership with the departments of health in New South Wales (NSW), Victoria and Queensland, Stillbirth Foundation, and Still Aware. The 'bundle of care' program is aimed at:

- improving detection and management of FGR;
- improving awareness and management of decreased fetal movement;
- reducing smoking in pregnancy;
- improving awareness of maternal safe sleeping position; and
- improving decision-making around timing of birth for women with risk.[14]

International models

6.13 The 'bundle of care' program is modelled on the United Kingdom National Health Service *Saving Babies Lives* bundle, which identified areas of substandard care and has resulted in a fall in stillbirth rates by one fifth in maternity units where the Care Bundle was implemented. It showed that, when the elements of care were

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10 Australian College of Midwives, *Submission 24*, [p. 5].

11 Professor Michael Permezel, Immediate Past President, RANZCOG, *Committee Hansard*, 9 August 2018, pp. 38–39.

12 Professor Homer, UTS, *Committee Hansard*, 8 August 2018, p. 34.

13 Stillbirth CRE, *Submission 56*, p. 10.

14 Stillbirth CRE, '"Bundle of Care": A bundle of care to improve mothers' and babies' health', https://www.stillbirthcre.org.au/resources/bundle-of-care/ (accessed 8 October 2018).

implemented as a package, greater benefits were achieved at a faster pace than if those improvements had been implemented individually.[15]

6.14 The Scottish AFFIRM study is assessing whether rates of stillbirth may be reduced by introducing an interventional package of care. It is aimed at increasing a pregnant woman's awareness of the need to promptly report decreased fetal movements, followed by a care management plan to identify possible placental issues, and timely delivery in confirmed cases.[16]

6.15 Whilst there are some good examples of continuity of care to be found, a lack of resourcing and understanding of the social and economic benefits of continuity of care inhibits wider acceptance of the model.

Public versus private health care

6.16 Mrs Doshni Stewart told the committee that a continuity of care model does not appear to be available in public hospitals and that, from the perspective of a pregnant woman, continuity of care is essential because the midwife knows her medical history and is able to implement a care plan taking account of risks.[17]

6.17 Dr Michael Gannon stated that many women do not have access to private maternity care, and that further work needs to be done in developing innovative public care models that seek to overcome the mortality gap.[18]

6.18 A recent study comparing perinatal mortality between public and private hospital care showed that mortality occurred more frequently in public care, although the disparity was not explained by population differences. Whilst differences in clinical practices seemed to be partly responsible, further research was needed to examine whether the private hospital obstetrician-led continuity of care model would improve outcomes in Australia.[19]

6.19 Dr Nisha Khot, a medical practitioner in the public health system, noted that appointments generally last for 15 minutes, and a pregnant woman will generally not

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15 Australian Health Ministers' Advisory Council (AHMAC), *Strategic Directions for Australian Maternity Services*, Consultation Paper no. 2, 2018, p. 11.

16 AFFIRM: 'Can promoting Awareness of Fetal movements and Focussing Interventions Reduce fetal Mortality'; see J Norman, S Stock and A Heazell, 'The AFFIRM trial for prevention of stillbirth', https://www.tommys.org/our-organisation/research-by-cause/stillbirth/affirm-trial-prevention-stillbirth (accessed 22 October 2018).

17 Mrs Doshni Stewart, *Committee Hansard*, 9 August 2018, p. 15.

18 Dr Michael Gannon, *Committee Hansard*, 10 August 2018, p. 37.

19 N Adams, D Tudehope, KS Gibbons, et al, 'Perinatal Mortality Disparities Between Public Care and Private Obstetrician-led Care: A Propensity Score Analysis', *British Journal of Obstetrics and Gynaecology*, vol. 125, no. 2, January 2018, p. 156, https://obgyn.onlinelibrary.wiley.com/doi/pdf/10.1111/1471-0528.14903 (accessed 22 October 2018).

see the same doctor for every appointment. She suggested that there should be a process for identifying those who need lengthier appointments.[20]

6.20 Mrs Tiffany McIntosh considered that the approach to her care in the public system most likely contributed to her baby's stillbirth. When comparing her experience with private care in her two subsequent pregnancies, she concluded that continuity of care with the same doctor had been an important factor in their positive outcomes.

> When you're seeing different doctors, you report that you're experiencing a symptom: 'Oh, okay. If it keeps happening, make sure you let us know.' But then, when you go to your next appointment, it's a different doctor.[21]

Rural and regional care

6.21 The burden of stillbirth is borne disproportionately by women in circumstances of socio-economic disadvantage, Aboriginal and Torres Strait Islander families, those living in rural and remote areas, and those who have difficulty in accessing antenatal care.[22]

6.22 The lack of continuity of care is particularly acute for women in rural and regional centres, and has been exacerbated by the closure of small rural maternity services forcing pregnant women to travel long distances away from their family in order to receive care with negative impacts on their maternal health and wellbeing. The National Rural Health Alliance reported that:

> …to avoid the family distress women in rural and remote areas…do not report pregnancy, avoid antenatal care so they will not be recognised by the system and then present late for care, consequently risks to maternal and fetal health can be missed.[23]

6.23 Dr Khot suggested that a model could be introduced whereby a health expert in the city could liaise with local practitioners say, by teleconferencing, rather than the pregnant woman having to travel to a city for care not available in their own locality.[24]

6.24 Whilst communicating with women via the internet or telephone may not be ideal for those living in rural and remote communities where community-based care and support is desirable, there are circumstances where it may be the best option.

> …I think we need to have strong hub-and-spoke models for providing the tertiary care when it's needed. For example, we do telemedicine with Royal

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20 Dr Nisha Khot, *Committee Hansard*, 9 August 2018, p. 16.

21 Mrs Tiffany McIntosh, *Committee Hansard*, 9 August 2018, p. 16.

22 Professor Euan Wallace, Carl Wood Professor and Head of Department of Obstetrics and Gynaecology, Monash University, *Committee Hansard*, 9 August 2018, p. 25.

23 National Rural Health Alliance, *Submission 57*, [p. 7].

24 Dr Khot, *Committee Hansard*, 9 August 2018, p. 16.

> Darwin, and we're very cognisant of the huge burden that it is for women to travel for a suspected diagnosis of fetal abnormality. Yet if we can either make the diagnosis—or, in many cases, reassure them that there is no abnormality—it saves that family the enormous burden, financial and emotional, of having to travel to one of the major centres.[25]

Culturally appropriate models of care

Aboriginal and Torres Strait Islander families

6.25 The Department of Health's evaluation of qualitative studies in Australia and Canada in 2017 found that the best continuity of care model for Aboriginal and Torres Strait Islander families was one where there were strong community links and control by Aboriginal and Torres Strait Islander communities. It recommended that mainstream services such as GPs and public hospitals should 'embed cultural competence into continuous quality improvement'.[26]

6.26 The Stillbirth CRE reported that it has established an Indigenous Advisory Group which, while still finalising its terms of reference, aims to develop strategies to prevent stillbirth, provide better information about choices, and culturally appropriate models of care for Aboriginal and Torres Strait Islander women and families. The expectation is that it will have Indigenous leadership and work in a partnership model, build capacity amongst Aboriginal and Torres Strait Islander staff in maternity care, and advise on culturally appropriate models of care to prevent stillbirth.[27]

Closing the gap in stillbirth rates

6.27 Stillbirth CRE noted that culturally relevant strategies needed to be developed in partnership with Aboriginal and Torres Strait Islander researchers and communities, recognising that pregnancy 'is a key window to address the intergenerational impacts of racism, trauma and disadvantage'. Specific areas highlighted for attention included early and adequate antenatal care for Aboriginal women to ensure health and social issues are addressed early and supported with appropriate models of care; infection prevention and control; smoking-cessation programs; and obesity (and nutrition) strategies.[28]

6.28 A 2014 study of stillbirth rates amongst Aboriginal and Torres Strait Islander and non-Indigenous women in Queensland made similar findings.

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25 Professor Susan Walker, Head, Department of Obstetrics and Gynaecology; Chair, Women's and Newborn Health Network, Melbourne Academic Centre for Health, *Committee Hansard*, 9 August 2018, p. 26.

26 Department of Health, *Evidence Evaluation Report: Models for Aboriginal and Torres Strait Islander Women's Antenatal Care*, 16 May 2017, p. 4.

27 Stillbirth CRE, *Submission 56.1*, [p. 1].

28 Stillbirth CRE, *Submission 56*, [p. 13].

> High-quality antenatal care at all levels using culturally appropriate service delivery models that incorporate diabetes management, smoking cessation, STI screening and treatment, folic acid and fetal growth monitoring hold some promise of helping to improve pregnancy outcomes for Indigenous women.[29]

6.29 Professor Craig Pennell, Chair of the Red Nose National Scientific Advisory Group, noted that Red Nose has invested $17.6 million into research into stillbirth and Sudden Unexpected Death in Infancy (SUDI) over the past 40 years and, for the past decade, the organisation has had Indigenous representation on the advisory group and has been working to build relationships with Indigenous leaders and experts to create cultural change in relation to managing stillbirth and SUDI risks.[30]

6.30 An evaluation of models undertaken for the Department of Health in relation to Aboriginal and Torres Strait Islander women's antenatal care concluded that a number of culturally appropriate care programs have been implemented around Australia, with positive outcomes.

6.31 The Aboriginal Maternal and Infant Health Service established in NSW to improve the health of Aboriginal women during pregnancy, for example, delivered a continuity of care model where midwives and Aboriginal health workers collaborated to provide a high-quality maternity service that is culturally sensitive, women-centred, and provided in partnership with Aboriginal people.[31]

6.32 The evaluation also found positive and cost-effective improvements to maternity care in a Northern Territory regional centre, where a midwifery group practice was introduced to provide continuity of care for women from remote communities who were transferred to the centre for antenatal care and birth. The practice resulted in women being more engaged with the health services through their midwives.[32]

6.33 Ms Sara Potter, Clinical Nursing Midwife, Maternity Ward, Katherine Hospital, noted that many of the women who attend the Katherine Hospital to give birth can live up to 600 kilometres from Katherine, much of it on unsealed road. She stated that the hospital supports a collaborative care model for providing antenatal care.

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29 I Ibiebele, M Coory, FM Boyle, et al, 'Stillbirth Rates Among Indigenous and Non-Indigenous Women in Queensland, Australia: Is the Gap Closing?', *British Journal of Obstetrics and Gynaecology*, vol. 122, no. 11, August 2014, p. 1481, https://obgyn.onlinelibrary.wiley.com/doi/epdf/10.1111/1471-0528.13047 (accessed 19 September 2018).

30 Professor Craig Pennell, Chair, National Scientific Advisory Group, Red Nose, *Committee Hansard,* 9 August 2018, pp. 22–23.

31 Department of Health, *Evidence Evaluation Report,* pp. 3–4.

32 Department of Health, *Evidence Evaluation Report*, p. 4.

> What we strive for is a seamless approach or, for the women, a seamless journey. That's looking at the origin of the antenatal care when they're coming in to us, and, when they go home back to their community or back to their local Aboriginal Medical Service that may well be a local service, that collaboration is then looking at the integration, coordination, and sharing of information between those health services.[33]

6.34 Dr Megan Cope, Senior Medical Officer, Wurli-Wurlinjang Health Service, confirmed the value of this team approach to antenatal care provided in partnership with the Katherine Hospital.[34]

Birthing on Country

6.35 *Birthing on Country* (BoC), a model of Indigenous maternity care operating in Canada for several decades, was first introduced in Australia in 2013. In 2016 a BoC maternity services program was launched as a partnership between the Australian College of Midwives, the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM), the University of Queensland and the University of Sydney. BoC is a community-driven solution to Closing the Gap, focusing on reducing the stillbirth rate and improving the general health and wellbeing of Aboriginal and Torres Strait Islander women.[35]

6.36 BoC was tailored to an urban setting in Queensland known as *Birthing in Our Community* (BiOC). It is conducted by the Mater Mothers Hospital in Brisbane, in partnership with two local Aboriginal Community Controlled Health Services—the Institute for Urban Indigenous Health and Aboriginal and Torres Strait Islander Community Health Service, Brisbane Limited.

6.37 There is no specific training for stillbirth and bereavement care in the BiOC program, although this is currently being discussed with Stillbirth CRE. BiOC aims to bring birth back to community and country, and offer safe and culturally appropriate maternity services for Aboriginal and Torres Strait Islander mothers and babies.[36]

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33 Ms Sara Potter, Clinical Nursing Midwife, Maternity Ward, Katherine Hospital, *Committee Hansard*, 5 September 2018, p. 8.

34 Dr Megan Cope, Senior Medical Officer, Wurli-Wurlinjang Health Service, *Committee Hansard*, 5 September 2018, p. 2.

35 Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM), *Submission 263*, pp. 4–5; Australian College of Midwives, 'Ground breaking Indigenous maternity services program *Birthing on Country* launched, 8 November 2016, https://www.midwives.org.au/news/ground-breaking-indigenous-maternity-services-program-birthing-country-launched (accessed 23 October 2018).

36 Mater Mothers, *Closing the Gap: Birthing in Our Community*, https://www.matermothers.org.au/mothers-news/news/february-2018/closing-the-gap-birthing-in-our-community; Institute for Urban Indigenous Health, *Birthing in Our Community (BiOC) Partnership*, http://www.iuih.org.au/Services/Child_and_Maternal_Health#birthing (accessed 2 October 2018); see also Stillbirth CRE, *Submission 56*, p. 13; Mater Misericordiae Ltd, answers to questions on notice, 6 September 2018 (received 14 September 2018).

> The BiOC model of care facilitates the development of trusting and respectful relationships with known members of the multi-disciplinary team (including social workers and psychologists) which supports individualised and responsive care.[37]

6.38 Research amongst Aboriginal and Torres Strait Islander communities indicates that women believe birthing on country will improve maternal and perinatal health outcomes, even though this challenges the Western concept of health care which focuses on medical technologies and medico-legal liability. The researchers have concluded that there needs to be a better understanding of the social, cultural and spiritual risk of not birthing on country.

> Indigenous women have stated that their relationship to the land is compromised by birthing in hospitals where many also feel culturally unsafe. Women also express a belief that the relationship between the new baby, siblings and father would be better if they were together for the birth. The health of Aboriginal and Torres Strait Islander Australians is integrally linked to their culture and the land, a link that is strengthened by birthing on their land. Enforced evacuation to distant hospital facilities breaks this link, precludes the presence of family and integration of traditional attendants and practices; and continues cultural disconnection into the next generation.[38]

Culturally and linguistically diverse families

6.39 Most research and data related to stillbirth tends to focus on the mainstream population. However, 34.6 per cent of mothers who experienced stillbirth were born in countries other than Australia (see Chapter 2).

6.40 Some researchers raised the importance of culturally safe health care practices, whereby carers are required to reflect on how their own culture, history and biases might influence the care they deliver to culturally and linguistically diverse (CALD) families. However, it was acknowledged that few health professionals understand or receive specific training in this area.[39]

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37 Dr Michael Beckmann and Maree Reynolds, Mothers Babies & Women's Health Services, Mater Misericordiae Ltd, answers to questions on notice, 6 September 2018 (received 14 September 2018). Key aspects include an Indigenous governance framework and 24/7 midwifery care in pregnancy to six weeks postnatal care by a named midwife supported by Indigenous health workers and an Indigenous team coordinator.

38 S Kildea and V Van Wagner, *'Birthing on Country' Maternity Service Delivery Models: A Rapid Review*, Sax Institute, March 2013, p. 14.

39 See for example, Ms Karel Williams, Committee Member, Australian College of Midwives, *Committee Hansard*, 7 September 2018, p. 30; Dr Joanne Walker, Director Policy and Strategy Development, National Rural Health Alliance, *Committee Hansard*, 7 September 2018, p. 35; Angela Brown, 'Midwives' and Aboriginal and Torres Strait Islander women's experiences with cultural care in the birth suite: an interpretative phenomenological investigation', PhD thesis, University of South Australia, 6 May 2016, pp. 19−20.

6.41 The Multicultural Centre for Women's Health recommended culturally and linguistically appropriate health care, education and support that include bilingual health workers and culturally appropriate health education activities and participatory approaches.[40]

6.42 Dr Jasmin Chen, Research and Executive Officer with the Multicultural Centre for Women's Health, argued that there is a need to listen to mothers and their families from non-English speaking countries to understand why pregnant women are less likely to access antenatal care in their first trimester.

> …we also need to hear and amplify the voices of migrant and refugee women within research and education…we need to listen to mothers and families. We need to let people tell their stories.[41]

Mothers of South Asian origin

6.43 Professor Euan Wallace, Carl Wood Professor and Head of Department of Obstetrics and Gynaecology, Monash University, described how changes to clinical practice at Monash Health had helped to reduce stillbirth in women born in South Asia. The hospital observed a significant increase in pregnancies amongst women of South Asian origin from about 2009 corresponding to the increase in South Asian students studying at nearby Monash University. Importantly, they accounted for all the stillbirths at the hospital.

6.44 Researchers noted that the increase in stillbirth risk at the end of pregnancy happened much earlier in women of Indian or South Asian descent than in other Australian women. This finding resulted in the introduction of a new guideline of care in which the women at risk were offered an earlier intervention than was standard practice. There have been no stillbirths in South Asian women at term since then.[42]

6.45 These findings suggest that care guidelines need to be tailored to particular women whose risks may differ from the majority, and points to the need for more research on stillbirth in relation to ethnicity.

> What's fascinating about the work is that women of South-East Asian descent—so Chinese, Vietnamese, Cambodian—have a 40 per cent lower risk of stillbirth than white Australian women, and we don't know why. It goes to Sue's point that to solve stillbirth we need discovery research. We need to understand why Indian babies are at high risk of stillbirth and why Chinese babies are at lower risk of stillbirth. We don't know.[43]

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40 Dr Jasmin Chen, Research and Executive Officer, Multicultural Centre for Women's Health, *Submission 70*, pp. 2−4.

41 Dr Chen, Multicultural Centre for Women's Health, *Committee Hansard*, 9 August 2018, p. 50.

42 Professor Wallace, Monash University, *Committee Hansard*, 9 August 2018, p. 29.

43 Professor Wallace, Monash University, *Committee Hansard*, 9 August 2018, p. 30.

6.46 A more detailed understanding of specific risk factors, combined with more granular data and standardised collection of data across Australia, could help stillbirth researchers to create a tailored program of pregnancy care and timing of delivery in the same way that Monash has successfully done with ethnicity.[44]

6.47 Mrs Stewart reported that, as a woman of South Asian background, her pregnancy was around two to three weeks shorter than that of Caucasian women and that the medical staff involved in her care seemed unaware of this prior to her stillbirth.

> This has serious implications for the management of women and their unborn babies, with potentially dire consequences. With a huge influx of migrants in Australia, there should be adequate management of racially based health markers to identify groups at risk and to alter their care plan accordingly. My recommendation, firstly, is that there be a system to alert all those caring for pregnant women to any new research that may be relevant to their work. Secondly, I recommend that, very early in pregnancy assessment, mothers be placed in appropriate risk groups and their care plan be put in place so that decisions or recommendations are met strictly in conjunction with the associated known risks.[45]

Support for bereaved families

6.48 Several voluntary services offer support for bereaved families following miscarriage, stillbirth or the loss of a baby, including Red Nose, Post and Antenatal Depression Association, and Stillbirth and Neonatal Death Support (Sands Australia). Sands Australia, for example, provides peer-to-peer bereavement support with different types of services provided to suit different needs, including in-hospital bereavement care.[46]

6.49 Mrs Lyndy Bowden, Caretaker CEO of Sands Australia, emphasised the importance of timely and accurate data to ensure that bereavement services are targeted appropriately and available for bereaved families in the longer term, 'because when your baby dies you don't forget'.[47]

> We have an older-loss group. Sometimes we will have someone who is in their 70s and doesn't know where their baby is buried. Sometimes they don't

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44 Professor Susan Walker, Melbourne Academic Centre for Health, *Committee Hansard*, 9 August 2018, p. 30. See above for discussion of the Stillbirth CRE 'bundle of care' program being developed for Australian hospitals.

45 Mrs Stewart, *Committee Hansard*, 9 August 2018, p. 8.

46 Mrs Janelle Marshall, General Manager Services, Sands Australia, *Committee Hansard*, 9 August 2018, p. 3; Sands: Miscarriage, stillbirth and newborn death support, http://www.sands.org.au/. See also The GroundSwell Project which aims to create a cultural shift in the way Australians respond to death and grief, http://www.thegroundswellproject.com/ (all accessed 10 October 2018).

47 Mrs Lyndy Bowden, Caretaker CEO, Sands Australia, *Committee Hansard*, 9 August, p. 2.

> even know what the sex of their baby was. We can walk them through how they can get that information. And they also look for that support. For some people it's the first time they've ever said the baby's name to someone. We're finding a lot of parents that are calling up or coming to the support group saying, 'I wish I'd known about you when our baby first died.' Because sometimes it's a couple of weeks, a couple of months or a couple of years. When they leave the hospital and go home, there's nothing in that space if they don't know about us.[48]

Hospitals and health centres

6.50 Dr Adrienne Gordon, Neonatal and Perinatal Medicine Specialist, Royal Australasian College of Physicians (RACP), recalled working in a rural centre where there was more of a team approach to assisting bereaved families, noting that this is more difficult to achieve in busier hospitals and in a 'fractured health system' that does not provide coordinated health care for individuals.[49]

6.51 Some hospitals have adopted strategies to ensure that hospital staff are aware of bereaved parents and families that have experienced a stillbirth so that they 'adjust their demeanour appropriately' when caring for them.[50] Strategies include flagging a stillbirth record in the hospital system, and placing a butterfly—the universal symbol of stillbirth—on the doors of suites where the baby has been stillborn, or on the cot of a surviving baby to indicate a multiple pregnancy where a sibling has been stillborn.[51]

6.52 Several witnesses and submitters reported significant differences in the standard of bereavement care received from their respective hospitals.

> …the hospital staff were outstanding in their support and compassion. We had the best of care and were allowed as much time as needed to stay with Coralie. We were provided with a refrigerated cuddle cot and given a private room away from the maternity ward. They further supported us with pastoral care, bereavement support, memory boxes and keepsakes and provided crucial advice on funeral arrangements and Centrelink payments.[52]
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> …
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> When my daughter was stillborn in 2002, the staff admitted they did not want to believe that she had died in utero, so convinced themselves that it was her heartbeat they were monitoring. The bereavement support we

48 Mrs Bowden, Sands Australia, *Committee Hansard*, 9 August, p. 4.

49 Dr Adrienne Gordon, Neonatal and Perinatal Medicine Specialist, Royal Australasian College of Physicians (RACP), *Committee Hansard*, 8 August 2018, p. 50.

50 Ms Terri Ryan, *Submission 124*, [p. 2].

51 Dr Gordon, RACP, *Committee Hansard*, 8 August 2018, p. 50.

52 Mrs Stewart, *Submission 229*, [p. 4].

received following her birth was terrible, the staff were uncomfortable and didn't know how to look after us.[53]

…

We wanted to make special mention of the compassionate acts of the midwives who assisted with Magnus' birth, their kindness and professionalism was outstanding, I will never forget the midwife who stayed to support me even though her shift had finished. She just stayed to hold my hand. The hospital provided bereavement midwife was on leave when Magnus was born but she was helpful and supportive when she returned from leave and got in contact.[54]

…

Three weeks after my daughter passed away, I received a call from the hospital saying that my daughter was due for a vaccination as she had not received it. I had to inform the person calling that I had a stillbirth and hence the call did not apply to me. This was not right. I should not need to have explained to the hospital that my daughter had died, the same hospital where I gave birth and where they registered my daughter's death.[55]

6.53 Concern was also expressed about the lack of privacy in hospitals for those experiencing stillbirth. Parents about to knowingly experience stillbirth are likely to be further traumatised by being placed in a labour ward with mothers who have given birth to live babies. Ms Alex Lowe stated:

…I knew that I had to go to hospital to birth my daughter and was admitted along with mothers who had live babies. I could hear their labour cries and the babies crying. Our room was silent.[56]

6.54 Some witnesses praised the support received from the Integrated Support After Infant Loss (iSAIL) clinic, which was established with private funding and offers coordinated meetings between the bereaved parents and clinicians or health professionals in the immediate period after stillbirth. Whilst that service is not available in many hospitals, it was considered a valuable model of care that should be available for everyone.[57]

They were fantastic in coordinating people to meet with us if we wanted to see a particular specialist or ask questions. Anything that we requested we felt that we had that opportunity. So I do think that we were particularly

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53 Ms Natasha Donnolley, *Submission 116*, p. 5.

54 Name withheld, *Submission 136*, [p. 4].

55 Name withheld, *Submission 12*, [p. 3].

56 Ms Alex Lowes, *Submission 78*, [p. 2].

57 Ms Britt Jacobsen, *Committee Hansard*, 8 August 2018, p. 8; Mr Samuel Haldane, *Committee Hansard*, 8 August 2018, p. 2; Dr Gordon, RACP, *Committee Hansard*, 8 August 2018, p. 50.

fortunate that we received very good care afterwards, but, from what I understand, that's not the norm.[58]

6.55 Dr Gordon established the iSAIL clinic in the Sydney local health district. She stressed the importance of a custom-designed clinic providing continuity in care for bereaved parents so that they do not have to repeat their story to different people. She also highlighted the need to involve parents in the death review process.[59]

6.56 Other submitters and witnesses offered a range of suggestions for improving the level of care and support in hospital for bereaved parents and their families following a stillbirth. These included:

- providing bereaved families with access to an appropriate private space in which to say goodbye to their baby and to receive support from a specially-trained person;[60]
- providing a 'cuddle cot' (a cooling device placed into the cot), enabling parents to have more time with their deceased baby and giving them the opportunity to make necessary decisions regarding autopsy and test procedures;[61]
- providing bereaved families with the opportunity to discuss the stillbirth and related issues in a follow-up consultation with clinicians or other health professionals, including the results of any post-mortem investigation; and giving parents the opportunity to acknowledge the hospital staff involved;[62] and
- ensuring that the information and terminology used when communicating with bereaved parents experiencing a stillbirth is accurate. In one case the bereaved parents were told they had lost a son and only discovered that their baby was a girl from the autopsy report. The invoice they received from the hospital was also insensitive, identifying the stillbirth as an 'abortion'.[63]

Returning home from hospital

6.57 Hospitals also need to have strategies in place to care for bereaved families after they have returned home. Stillbirth CRE considered that there needs to be better integration of hospital and community services following stillbirth, so that bereaved

58 Ms Jacobsen, *Committee Hansard*, 8 August 2018, p. 8.

59 Dr Gordon, RACP, *Committee Hansard*, 8 August 2018, p. 50.

60 Ms Alex Lowes, *Submission 78*, [p. 2]; Ms Ryan, *Submission 124*, [p. 2].

61 Mr Haldane, *Committee Hansard*, 8 August 2018, p. 4; Ms Stephanie Vowles, *Submission 101*, [p. 3].

62 Mrs Leanne Smith, *Committee Hansard*, 8 August 2018, p. 62.

63 Tim and Leanne Smith, *Submission 77*, [p. 2].

parents receive appropriate support when they transition from hospital to community care.[64]

6.58 Another witness expressed concern about the lack of follow up care from the hospital after they returned home. However, she was full of praise for the care she received whilst at the hospital, and highlighted the importance of bereaved parents receiving timely information and support.

> We were given a beautiful memory box to take home which we will always treasure. The box also contained a book from Pregnancy Loss Australia, with lots of information about giving birth to a stillborn baby, creating memories, services like Heartfelt and information about online support groups. I wish this book would have been given to me earlier, before my daughter was born. I found out about lots of services and ways to create memories when it was already too late. The two only photos we have of our daughter, apart from the hand and feet ones the midwives took, are from the pathology in South Australia and I cannot express how grateful I am for those.[65]

Listening to bereaved parents

6.59 One important facet of training for clinicians and other health professionals concerns how to listen to bereaved parents and encourage them to contribute their personal knowledge and experience following a stillbirth. As Mrs Clare Rannard explained:

> …in the aftermath I feel a great sense of frustration that I knew the story best, it happened to my body, I lived through the days and hours leading up to this event and I remember it very clearly, yet I was never asked to tell my version of events…It's also quite intimidating to face up continually to specialist consultant doctors who have the experience and the knowledge to explain things away. You feel small and you feel alone and unsupported on the other side of the table against medical hierarchy.[66]

6.60 Ms Terri Ryan pointed to the long-term consequences for women who do not raise their concerns and subsequently experience a stillbirth:

> No person is more qualified to tell a woman what is going on with her body than the mother. Too often women are ignored when they raise concerns. We have full medical insurance. The question becomes what harm would it have done to place me under observation and monitor the baby for 24 hours? 12 hours? I will forever feel the weight of NOT speaking up, being too complicit and trusting, not asking for more to be done.[67]

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64 Stillbirth CRE, *Submission 56*, p. 11.

65 Julia and Debden Whaanga, *Submission 108*, pp. 2–3.

66 Mrs Clare Rannard, *Committee Hansard*, 8 August 2018, p. 8.

67 Ms Ryan, *Submission 124*, [p. 1].

6.61 The experience of a stillbirth commonly results in significant emotional stress in subsequent pregnancies and postnatal anxiety and depression. Indeed, research suggests that women who have experienced a stillbirth have a five-fold increased risk of stillbirth in subsequent pregnancies.[68] As one witness described it:

> The stress and anxiety of the pregnancy took a severe physical and mental toll on me. I would lay awake at night monitoring Obie's movements, I would have panic attacks and late-night rushes to emergency because I thought something was wrong. It was exhausting and terrifying. I wouldn't buy baby items or set up a nursery—I was convinced I would lose another baby (it was all I'd ever known). I would see my doctor for fortnightly and then weekly ultrasounds and fought tooth and nail for an early induction.[69]

Bereaved fathers

6.62 Several witnesses noted that bereaved fathers are often overlooked in the provision of advice, education and support. The implication is that they should be able to cope with the loss while providing support for their partner. As one submitter put it:

> Although support for bereaved mothers needs improvement, there is barely any support for a bereaved father. Men need hand holding through this trauma too.[70]

6.63 Sands Australia reported that bereaved fathers' grief responses may be quite different to those of bereaved mothers, in that they may feel that they need to be strong and supportive and put their own grief on hold. They may also feel that their grief is dismissed.[71] One bereaved father explained the need for better education and care for fathers experiencing the stillbirth of their baby.

> As a father, I have often felt left behind in this journey and it has often seemed that stillbirth is a women's issue. Listening to parts of yesterday's session in Sydney, I rarely heard about the impact on dads. I rarely hear dads mentioned and, invariably, we seem to get lumped in with families and partners. I am saddened to see, as I look at the committee, that there is no male presence either. One of the most important things that was said to me after the loss of our son was by our midwife, who came into our room and said, 'You won't understand this now, but you will in time: hello, mum and dad.' At the time, it seemed like a bizarre statement. As dads, we carry our own grief and, too often, we put this aside to support our partners. We are told to be strong for our wife, for our partner, for our families; we are usually asked how the wife is and rarely are we asked how we are. I can't recall the last time someone called me to see how I am doing. There is little research into the impact of stillbirth on dads, and dads seem to be resistant to attending support groups and seeking counselling. We need to find a way

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68 Stillbirth CRE, *Submission 56*, p. 12.

69 Samantha and Aaron Isfahani, *Submission 121*, p. 4.

70 Ms Natasha Hulse, *Submission 211*, p. 9.

71 Mrs Marshall, Sands Australia, *Committee Hansard*, 9 August 2018, p. 5.

> to engage dads in a way that will support them in our grief journey. Engaging in conversations around stillbirth that seem to imply that stillbirth is women's issue doesn't help; we have had our loss as well.[72]

6.64 Ms Kate Obst, a researcher at the University of Adelaide, reported on recent studies into the psychological impact of pregnancy loss on men. She noted that bereaved fathers received variable levels of support, but a consistent theme was a lack of recognition of their experience, either by the healthcare system and workplaces upon return to work, or amongst family, friends and the community.[73] Ms Obst suggested a range of strategies for more male specific and informal support options, including male support workers in hospitals and 'more blokes on pamphlets' to normalise support for men affected by stillbirth.[74]

6.65 Mr Adam Flanagan suggested that innovative approaches such as 'wilderness therapy' might help grieving fathers. He noted that a large proportion of couples break up after a loss, and that grieving men need ways to address their anger, regret and pain. He suggested that men may find it easier to interact and disclose their experiences and needs through shared activity, 'shoulder to shoulder rather than face to face'.[75]

Bereaved siblings and grandparents

6.66 Antenatal education and post-stillbirth care tends to focus on the needs of the mother, but there has been little attention given to the experiences of bereaved siblings, grandparents and other family members. Emerging research suggests that educational programs about stillbirth are required and need to be tailored to their needs.[76]

6.67 The PriceWaterhouseCoopers study found that there were significant flow-on effects of a stillbirth for other children, grandparents, extended family and friends (see Chapter 3).

> Siblings and grandparents in particular were affected negatively by stillbirth. Some family members sought counselling to deal with the negative effects: ‘My Father in law was very sad & depressed by the stillbirth of his first grandchild. So much so that he sought counselling’; ‘My mum was highly affected by the loss...She was her first grandchild and she really struggled to be there for me as her grief was so intense…’; ‘Parents on both sides were profoundly impacted and depressed, some had

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72 Mr Bruce McMillan, *Committee Hansard*, 9 August 2018, p. 9.

73 Ms Kate Obst, PhD/Master of Psychology (Health) Candidate, School of Psychology, University of Adelaide, *Committee Hansard*, 10 August 2018, p. 17.

74 Ms Obst, University of Adelaide, *Committee Hansard*, 10 August 2018, p. 17.

75 Mr Adam Flanagan, *Submission 122*, p. 2.

76 Ms Kate Obst, Dr Clemence Due and Dr Melissa Oxlad, *Submission 28*, [pp. 1−2]; Ms Vowles, *Submission 101*, [p. 10].

> to seek therapy…'; '...my best friend was put on anti-depressants. All my friends rallied around us and it had financial and mental impacts on many people'.[77]

6.68 Studies conducted at the University of Adelaide have found that, whilst grandparents are very often the first people to be called upon to support the bereaved parents, most have no knowledge or experience of stillbirth. Researchers noted that many experienced a lack of recognition of the 'overwhelming and long-lasting' grief of stillbirth, and noted the lack of information about support services that may be available for bereaved grandparents.[78]

6.69 Other children in the family are also likely to be deeply affected by the stillbirth of a sibling, and may need support and counselling to help them with their grief. Julia and Debden Whaanga described the long-lasting impact on their family.

> Our two children are still grieving for their little sister and had lots of behavioural changes after the loss of our daughter. It would have been very helpful to have information about children and grief on hand from day one.[79]

Culturally appropriate bereavement care

Aboriginal and Torres Strait Islander families

6.70 Aboriginal and Torres Strait Islander women in Australia experience twice the rate of stillbirth as non-Indigenous women (see Chapter 2), yet their experiences of stillbirth are often overlooked. CATSINaM noted that there are no specific guidelines or policies on bereavement care for Aboriginal and Torres Strait Islander Australians, and recommended that guidelines should be developed as part of culturally safe maternity care services, consistent with the BoC model of care.[80]

6.71 Evidence suggests that bereavement support for Aboriginal and Torres Strait Islander women experiencing stillbirth needs to be tailored to their particular circumstances, given that they often come from different places and speak different languages.

> They are absolutely suffering with the highest rates of stillbirth, yet they're overlooked, and I think that's a huge cry for help. So this issue needs funding, counselling services and, to repeat what Jane said, major reform of

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77 PriceWaterhouseCoopers, *The Economic Impacts of Stillbirth in Australia*, September 2016, p. 15.

78 Dr Melissa Oxlad, Lecturer, School of Psychology, University of Adelaide, *Committee Hansard*, 10 August 2018, p. 17.

79 Julia and Debden Whaanga, *Submission 108*, [p. 5].

80 CATSINaM, *Submission 263*, p. 5.

> not just midwives but midwifery students, medical students and doctors—they don't do this well.[81]

6.72 For bereaved families there may be particular cultural or religious sensitivities in relation to autopsies and the timing of burial. Ms Potter pointed to a general lack of understanding in the health profession about how Aboriginal and Torres Strait Islander people view stillbirth, bereavement and care after their babies are born. She noted that particular care needs to be taken to provide stillbirth education that is for the whole community rather than focusing just on educating women.

> As a health professional and from my experience, I'm not sure that we, as care providers, have a comprehensive understanding of what Aboriginal people see as a stillbirth, what their feelings are around stillbirth and, therefore, what their ideas would be around bereavement and care after their babies are born. To have knowledge around that would be invaluable. I don't think we do at the moment.[82]

6.73 In 2017 the Townsville Hospital and Health Service and James Cook University commenced a study to address the gap in fetal autopsy rates for Aboriginal and Torres Strait Islander and non-Indigenous stillbirths. The study was undertaken in recognition of the higher rates of stillbirth for mothers in the Aboriginal and Torres Strait Islander population (13.3 stillbirths per 1000 compared to 7.1 deaths per 1000 for non-Indigenous mothers), and lower rates of fetal autopsy observed in Queensland (28.5 per cent of Indigenous parents consent to autopsy following stillbirth compared to 38.9 per cent for non-Indigenous parents). The aim was to explore culturally appropriate ways to approach Aboriginal and Torres Strait Islander families for consent to autopsy following stillbirth and develop guidelines for health care providers.[83]

6.74 Preliminary results indicated an autopsy rate of 25 per cent for Aboriginal and Torres Strait Islander women in the study, which is well below the overall rates in Queensland and other states. It summarised the reasons women and families declined an autopsy as follows:

- not asked in a culturally appropriate manner;
- not enough time to think about giving permission; and
- not wanting baby 'cut up'.[84]

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81 Mrs Rachelle Martin, *Committee Hansard*, 10 August 2018, p. 10.

82 Ms Potter, *Committee Hansard*, 5 September 2018, p. 9.

83 Queensland Health, 'Stillbirth study aims to help close the gap', *Media release*, 14 August 2017; Department of Neonatology/Maternal Fetal Medicine, The Townsville Hospital and Health Services, *Submission 44*, [p. 2].

84 Townsville Hospital and Health Services, *Submission 44*, [p. 4].

Culturally and linguistically diverse families

6.75 Professor Pennell noted that one in three women who give birth in Australia are born outside of Australia while the rate of stillbirth amongst such women is double and even triple that of Australian-born women, depending on their background. He argued that stillbirth education needs to be better targeted to meet their particular needs.[85]

6.76 Dr Clemence Due, Senior Lecturer, School of Psychology, University of Adelaide, noted that pregnancy loss and stillbirth impacts on a range of groups, but that there is very little research into the role of grief and support following stillbirth for men and women from CALD backgrounds in Australia.

> In summary, while we know something of the needs of heterosexual women following stillbirth, there remain very large gaps in our knowledge concerning the psychological impact and support needs of nearly all other people impacted by a stillbirth, and we would advocate for further research for these groups to ensure that whole families are supported in the event of a stillbirth.[86]

6.77 The 2018 Victorian Parliamentary Inquiry into Perinatal Services found that support for CALD communities is variable and dependent upon the availability of local services. It heard evidence about how women from CALD communities and refugee communities face particular disadvantages and barriers in accessing perinatal services as a result of:

- social isolation and vulnerability to developing mental health conditions during the perinatal period;
- difficulty in receiving support and services needed;
- difficulty communicating and navigating health and social services;
- inexperience of health professionals in working with CALD families; and
- insufficient use of interpreters to support women during consultations and in hospital.[87]

6.78 Some programs in Australia are being designed to meet the needs of people from CALD backgrounds. For example Stillbirth CRE, in partnership with stillbirth research and advocacy groups, has begun a program which gives migrants and refugees access to face-to-face support visits with interpreters and information translated into community languages.[88]

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85 Professor Pennell, *Committee Hansard*, 9 August 2018, p. 19.

86 Dr Clemence Due, Senior Lecturer, School of Psychology, University of Adelaide, *Committee Hansard*, 10 August 2018, p. 16.

87 Parliament of Victoria, *Inquiry into Perinatal Services: Final Report*, Family and Community Development Committee, June 2018, p. 321.

88 Australian College of Nursing, *Submission 20*, pp. 4–5.

6.79 Dr Chen reported that the Multicultural Centre for Women's Health specialises in providing bilingual outreach health education for women. She pointed out that the trauma of stillbirth is compounded for mothers and their partners whose primary language in not English, and who may not have the support networks of family and friends in Australia. Dr Chen highlighted that there is limited stillbirth education and advocacy available for them, in part because of the culture of silence surrounding stillbirth and the lack of funding for translating educational materials in culturally appropriate ways.

6.80 Dr Chen discussed the Centre's success in conducting bilingual outreach programs on other health issues, and argued that partnerships involving mothers and parents as co-researchers, leaders and experts are likely to deliver the most effective and meaningful stillbirth education campaigns and initiatives.[89]

> For example, in an unrelated project that I worked on, on palliative care, we went out and did focus group work with five different communities to try and understand more about their thoughts about grief and grieving, their ideas about health as well, and how that might affect the messages that we delivered to them and the approaches that we took. I think that probably goes a long way to explaining why this hasn't been really discussed through our service. It may be that it has been in other services but we're quite unique, in terms of the work that we do.

Committee view

6.81 Women experiencing socio-economic disadvantage, Aboriginal and Torres Strait Islander families, those living in rural and remote areas, and women from CALD backgrounds who may have difficulty in accessing antenatal care are more likely to experience stillbirth in Australia.

6.82 The rate of stillbirth for Aboriginal and Torres Strait Islander babies is unacceptably high, and requires a focused national effort to address the contributing factors. The committee acknowledges the importance of birthing on country in delivering community driven solutions. It is now widely recognised that the best continuity of care model for Aboriginal and Torres Strait Islander families is one where there are strong community links and control by Aboriginal and Torres Strait Islander communities. Providing culturally appropriate continuity of care for Aboriginal and Torres Strait Islander communities is therefore a high priority.

6.83 International initiatives, such as the mandatory government requirement in Scotland for clinicians to discuss fetal movement and stillbirth with all pregnant women at antenatal appointments from 20 weeks' gestation, have been successful in reducing stillbirths and provide a valuable model for creating a cultural change in relation to stillbirth in Australia (see Chapter 7).

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89 Dr Chen, Multicultural Centre for Women's Health, *Committee Hansard*, 9 August 2018, pp. 50–51.

6.84 As part of this cultural change, mainstream health and hospital services should be encouraged to embed cultural competence in their protocols and training for clinicians and other health professionals.

Recommendation 8

6.85 The committee recommends that, through the Australian Health Ministers' Advisory Council, the Australian government leads a process to develop a national culturally and linguistically appropriate continuity of care model aimed at reducing the rate of stillbirths in Australia, particularly amongst groups identified as having a higher risk of stillbirth.

6.86 The Department of Health should contribute to this process by undertaking a review of Australian and international models of culturally and linguistically appropriate care, and identify examples of best practice that have successfully reduced the incidence of stillbirth amongst Aboriginal and Torres Strait Islander women, women from rural and remote regions, and women from CALD communities.

6.87 Given the high rate of stillbirth amongst women from Indigenous backgrounds, bereavement care guidelines need to be developed with public hospitals and health centres, in consultation with local communities, to ensure that they are culturally and linguistically appropriate and embedded within a cultural safety framework and consistent with the BoC model of care.

6.88 Successful programs of bereavement care are already available in some hospitals, such as the iSAIL clinic which offers coordinated meetings between the bereaved parents and clinicians or health professionals in the immediate period after stillbirth. However, culturally appropriate bereavement support services should be available for all parents who have experienced stillbirth, and such services should be better integrated with community services so that bereaved parents receive appropriate support when they transition from hospital to community care.

6.89 The preliminary findings of the 2017 study undertaken by Townsville Hospital and Health Service and James Cook University indicated reasons for low autopsy rates amongst Aboriginal and Torres Strait Islander families, and these findings should be taken into account when preparing guidelines for culturally appropriate bereavement support in hospitals and health centres.

6.90 The committee acknowledges that a lack of resources limits the capacity for hospitals to locate and work with Aboriginal and Torres Strait Islander parents who have experienced a stillbirth, and notes that some may be transient or live hundreds of kilometres from the health service.

Recommendation 9

6.91 The committee recommends that the Department of Health, in consultation with local communities, develops national best practice guidelines for hospitals and health centres on providing culturally appropriate support and information for bereaved families who have experienced stillbirth, drawing on

successful models such as the Integrated Support After Infant Loss clinic. The guidelines should include provision for bereavement support and address the specific needs of:

- **bereaved fathers, siblings, grandparents and other family members;**
- **families from rural and remote communities;**
- **Aboriginal and Torres Strait Islander families; and**
- **families from culturally and linguistically diverse backgrounds.**